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LONG-TERM CARE AND ACCESS TO HEALTH CARE: THE WEST VIRGINIA EXPERIENCE

HEARING

BEFORE

THE PEPPER COMMISSION

U.S. BIPARTISAN COMMISSION
ON
COMPREHENSIVE HEALTH CARE

ONE HUNDRED FIRST CONGRESS

FIRST SESSION

CHARLESTON, WV

DECEMBER 13, 1989

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LONG-TERM CARE AND ACCESS TO HEALTH CARE: THE WEST VIRGINIA EXPERIENCE

WEDNESDAY, DECEMBER 13, 1989

THE PEPPER COMMISSION
U.S. BIPARTISAN COMMISSION ON
COMPREHENSIVE HEALTH CARE
Charleston, WV.

The Commission met, pursuant to notice, at 10 a.m., in the auditorium of the Health Sciences Center, West Virginia University, Charleston, WV, Hon. John D. Rockefeller IV (Chairman of the Commission), presiding.

Present: Senator John D. Rockefeller IV.

Also Present: Judith Feder, staff director; Edward F. Howard, general counsel; Steven C. Edelstein and Philip Shandler, professional staff.

Chairman ROCKEFELLER. Bea, I'm told, was really helpful in making it possible for so many people to attend this morning. I thought we were going to have an 8-inch snowstorm, but we didn't. It was only about 6 inches. [Laughter.]

So to all of you that came, I'm really proud about that.

And this is a very important hearing. Obviously, it's one that means an enormous amount to me simply because I represent West Virginia in the U.S. Senate. And, even though I'm lucky enough to be chairman of the Pepper Commission—in fact, to have taken Claude Pepper's position as chairman of the Bipartisan Comprehensive Health Commission—I know where I come from and I know whom I represent. I'm very, very happy to see so many of my fellow West Virginians here today.

So, let's get this hearing started. We've got a very long hearing, which is going to require some discipline on my part and on the witnesses' part. I will be easy, because I will be listening and only asking a few questions of the witnesses.

We're meant to be through by about 12:45 p.m., which is going to be tough to do.

Bea is going to be one of our last witnesses. Well, we'll give her about 3 minutes. [Laughter.]

You did a great job, Bea. I wanted to thank you.

Ms. BURGESS. Thank you.

OPENING STATEMENT OF CHAIRMAN JOHN D. ROCKEFELLER IV

Chairman ROCKEFELLER. Let me open this with a statement. This is a hearing as you know about long-term care and the uninsured, which is a massive, massive American problem.

In fact, I do not know of any single individual problem more compelling, more overwhelming, more devastating, more embarrassing to our Nation, than the problem of 37 million Americans without any health insurance whatsoever, including 12 million American children. In fact, 32 percent of all of the people in West Virginia who do not have health insurance are children. One-third of all the people in West Virginia who do not have health insurance are children.

This is called America. This is something that happens in no other industrialized country. It does happen here. It cannot be allowed to continue to happen here. That is what the Pepper Commission is about.

People in the Congress are looking to us. The White House is looking to us. The American people are looking to us to come up with a solution for that problem and one other which is tremendously difficult. That's called long-term care for those who need it.

It is not necessarily people who just might be 65 years or older. It might just as easily be about an 8-year-old kid who has developed mental disabilities, or I might be talking about a 40-year-old young man who has cerebral palsy. I might be talking about a lot of people in this country who need long-term care, do not have long-term care, and cannot get long-term care, unless they have a lot of resources.

Those are monumental jobs. There is a possibility that the Pepper Commission—and this is something that I will decide—there is a possibility that the Pepper Commission may take up, once again, way before anyone thought the subject would reemerge, the subject of catastrophic health insurance.

People thought that was dead and buried as of this session. It is my reading that the need for catastrophic health insurance—whether people interpret it as long-term care, or as indeed exactly what it says, catastrophic care, prescription drugs, and the rest of it—that that need did not go away simply because the Congress refused to sustain the legislation. We may very well come back with a solution to that particular problem. [Applause.]

I have to tell you we didn't do a very good job of communicating what it was that we did. There are a couple of groups around the country that didn't do a very good job themselves of communicating what we did. We think that this is a serious issue. It is not decided by the Commission whether we are going to address it or not. It is my own inclination that we ought to. We are going to do about everything else. We might as well do that too.

First of all, I have got to apologize to everyone here, because we were meant to have this hearing earlier. We didn't because of the fact that the Senate unexpectedly stayed in session. A lot of people had their hopes up, but then I had to postpone the hearing planned for October because the Senate remained in session. We were discussing physician payment reform and other basic changes in health care and Medicare. I couldn't leave, and I really apologize about that.

The Pepper Commission, as some of you know, was created by an act of Congress. In fact, it was a creature of the catastrophic health care bill. Claude Pepper put this Commission into the catastrophic health bill because he wanted to see long-term health care devel-

oped, and he was afraid that nobody would have the guts to come up with a plan.

His provision created a summit level Commission made up of only 15 people. Six, if I might say so, are six key health players from the Senate. There are then six key health players from the House, and three appointed by the administration. Only 15 of us.

We will be at work, for example, tomorrow, from 8 o'clock in the morning, to 5 o'clock in the afternoon in a special meeting. We will be rolling up our shirtsleeves, and working on getting toward what it is that we want to do, looking at the options, beginning to make the hard decisions.

You have no idea, over the summer, how long and hard we have been working at this—meeting early in the morning, hour upon hour, shirtsleeves rolled up, in mostly very private meetings, so that we could really get down to the business of trying to solve these incredibly hard problems which nobody has ever before been able to solve.

What we want are feasible, national approaches which will make sure that all Americans have access to health care, and that all Americans who need it have long-term care. That is no small task.

I am committed to making this report a consensus report. On our Commission we have members with various ideologies, various philosophies, various approaches. I want a consensus report. I am working very hard toward a consensus report as chairman, because, realistically, it is only when you can develop a consensus that you then can pass something through the Congress and have it signed by the President. In other words, you can have a wonderful report which did everything you wanted, and everything that I might, I agree with, but if it can't pass by Congress, or by the President, of what use would it be? None whatsoever.

It is a consensus report that we are searching for. It a consensus report that we are going to get.

We have heard a lot of testimony. It has been moving, disturbing, emotional testimony where people have bared their souls. We have had some very rough sessions, in terms of hearing, dealing with the hurt and the anger and the frustration that people across this country have. Some of them are heroic stories from people who have day by day been coping with, both financially and emotionally, the burdens caused by these health care problems.

We all pay. If the least of us is weak, then the strongest amongst us is weak. When it comes to health care, if some don't have it, then we are all victims, one way or another.

We are trying to create a healthier, stronger America, and if we fail to do that, you know, we have nobody to blame but ourselves.

People sometimes say: "What is access to health insurance? What is access to health care? What does that mean?"

I recall a lady in Minnesota, who testified in one of our hearings. She had been pregnant—she told us the story herself—and when she began having labor pains, she and her husband got in the car. She left for the hospital, for her neighborhood hospital. Her neighborhood hospital wouldn't accept her, because she didn't have health insurance. She was told to "go down the road," about 84 miles, to the public hospital. They did that, and they got there, but

by the time they had gotten there, the baby had been born, and later died.

If you want to know what access to health insurance is, my guess is that this woman will give you an answer with a tremendous amount of emotion and feeling.

This is what we are dealing with. It is a hidden problem, because most people do have health insurance, and therefore most people don't pay attention to those that don't have health insurance.

We are determined to try and find a way. There were some in fact who suggested that we totally gut the entire American health system and start all over again. That was a nice thought, but it never would have cleared Congress. We would have never developed a consensus. It would have never been signed by the President. It would not have been realistic. It would have been, therefore, an exercise in absolute futility.

What we are trying to do is to get an answer enabling us to solve the problems, develop the consensus, pass the program, have it signed into law by the President. It won't all happen, immediately, because of the magnitude of what we are confronting here. We are probably talking about a number of years to accomplish this. That's all right. We have never had a blueprint before, and the Pepper Commission is going to give us a blueprint. It is going to do it by March 1, 1990, which as I count it, is about 2½ months away. [Applause.]

Let's go right away to our witness list. Ed Howard, behind me, is not only an expert in health care, but is also a lawyer, aren't you Ed?

ED HOWARD. Yes; but if it helps, I'm not much of one.

Chairman ROCKEFELLER. Yeah, but he says if it helps, he's not a very good one, depending on your point of view. Steve Edelstein, over there, was tremendously helpful in setting all of this up. Mary Ella Payne, who works with me, who is right here, is in fact a registered nurse and got her masters in public health at North Carolina University, and is terrific.

We have five panels: individual witnesses; the national perspective; the West Virginia perspective; innovative programs; and interest groups and organizations. Those are our five. Our challenge is to do this and finish it by 12:45 p.m., which I guess means that I better shut up. So, first let's go to individual witnesses: Charles Keeney, from Charleston, WV; Debbie Belcher-Smith—about whom there was an article in the paper—from Charleston, WV; and the Reverend Daniel Edward Oakes, also from Charleston, WV. We welcome each of you and if we go alphabetically, I guess, Debbie, you'll be first, because Belcher comes before either Keeney or Oakes.

Ms. BELCHER-SMITH. Smith.

Chairman ROCKEFELLER. I really do welcome you and look forward to hearing your testimony.

Ms. BELCHER-SMITH. Good morning.

AUDIENCE. Good morning.

Chairman ROCKEFELLER. Now, the first thing to do is pull the mike right up close. This is a microphone-friendly hearing.

STATEMENT OF DEBBIE BELCHER-SMITH, CHARLESTON, WV

Ms. BELCHER-SMITH. Senator Rockefeller, my name is Debbie Belcher-Smith. I live in Charleston, WV, with my husband and our 16-year-old son. My parents, George and Henrietta Belcher, they live next door to us.

Chairman ROCKEFELLER. Debbie, you're going to have to still speak up a little bit.

Ms. BELCHER-SMITH. About 7 years ago, my mother, at 46, had a massive stroke. For 9 months, she lay in the hospital in a coma. My father, myself, and other family members took turns doing the work of a private duty nurse. One of us was there at all times, 24 hours a day. At that time, I changed my shift and went on nights, so I could be there with my mother during the day, so my dad could have a break, and he would stay all night.

The doctors told us that she would never wake up, so my father made the decision to take her home in the coma. But before that could be arranged, she came out. We looked into hospitals which specialize in rehabilitation of inhead injuries. Although my mother's mental condition was good, she was completely paralyzed on her left side.

We were hoping to find a place that would help her learn to walk again. According to their representative, and their brochures, a hospital in Massachusetts seemed to offer the care my mother needed. They said that she would have 3 to 4 hours of therapy a day. So we arranged for my mother to enter that facility when she was discharged from the hospital.

In reality, they turned out to be nothing more than a nursing home. They didn't have 3 to 4 hours of therapy a week, let alone 3 to 4 hours a day.

Had my father had the resources, he would have investigated it before we took my mother there. As it was, we lost valuable time in my mother's rehabilitation. After about 5 months, my father was so unhappy with the care she had received, that he brought her back home.

Equipping their home for her return was a major undertaking. Their house has two stories with all the bedrooms upstairs, so they tore down the garage and built a room for her on the first floor. They needed supplies like a hospital bed, a lift, a potty-chair, and wheel-chair. Although insurance helped with some of the costs, it was very expensive.

Caring for my mother is extremely difficult. My mother outweighs both me and my father by quite a bit. Lifting her is hard for him, and it is impossible for me. My father retired from the phone company with a work-related disability. He had a bad back. Every time he lifted her, he threatened his own health.

We had trouble finding outside help. Last year when my father had to go in for major surgery, we needed someone to stay with her while I was at work. We did find someone that did stay, but we found out that she wasn't what we thought she was.

My father's health is deteriorating now. He can't provide the care that he used to for her. He can no longer bend to pick up her bedpan, and he's been putting off surgery——

Chairman ROCKEFELLER. You take your time.

Ms. BELCHER-SMITH [continuing]. That he now needs very desperately.

Chairman ROCKEFELLER. You take a minute, Debbie, and go ahead. Just take a minute.

Ms. BELCHER-SMITH. Pardon me. They get by day by day. I help as much as I can, but I have my own family I must tend to. My father now pays a woman to stay during the week. She gives my mother her medications, prepares her meals, and bathes her. But she doesn't always see so well, so we have to get out my mom's medicine early, so that she can give it to her. My father pays her out of his pocket, in addition to my mother's prescriptions—which run about $300 a month.

All of this is taking a financial toll on them. He has already said there wasn't going to be much of a Christmas this year.

The real problem is that there is not a lot of help out there. Families are left to cope on their own. We have been able to cope better than others, since nursing care is not new to my family. My brother was born with cerebral palsy. He wasn't covered by insurance, and my parents would have never put him in a nursing home. They provided total care until he died at the age of 26. A nursing home would have seemed to be the only answer here, but they wanted you to sign over everything that you had, sometimes maybe your first born, before they let you in.

The truth is not everyone belongs in a nursing home. My mother is physically disabled, but mentally sharp. She doesn't need an R.N. She would need a doctor to come in maybe every other month for a checkup, but doctor's don't make house calls now. She can do better, for a lower cost, at home, and she is so much happier there. There aren't any nursing home beds available for short stays, like when my dad is in the hospital. Finding qualified people to come into the home is a major struggle.

We need better choices, and we need answers. I only hope that things change before I get old, or maybe disabled, so that my son doesn't have to go through what I am presently going through.

Long-term health care is not restricted to the elderly. It is for anyone who, that could possibly need this type of nursing care. That could mean a child, a husband, a brother, or sister. This is something that could affect all of us, at one time or another.

Something needs to be done now, through reappropriation of funds. Please give this matter your utmost consideration, because right now, I represent people who cannot speak for themselves.

Thank you. [Applause.]

Chairman ROCKEFELLER. Thank you, Debbie. Charles Keeney, why don't you go?

STATEMENT OF CHARLES KEENEY, CHARLESTON, WV

Mr. KEENEY. Good morning, ladies and gentlemen. My name is Charles Keeney. I live in Charleston. My position is that I am a parts-salesman for the N.A.P.A. Corp.

Chairman ROCKEFELLER. Mr. Keeney, could you get that microphone * * * thank you.

Mr. KEENEY. I feel fortunate that both of my parents are alive, although my father at 75 was diagnosed with Alzheimer's disease.

At that time, he was living with my mother in Elinor, WV, about 35 miles from Charleston. My mother tried to take care of him the best that she could, but I ended up going to Elinor often to help her. My father needed help with bathing, toileting, meal preparation, and dressing.

Last year, he suffered from a severe Parkinson episode and could not get out of bed for several days. This crisis brought us to realize my mother's caregiving limitations. We felt fortunate that at about this time our neighbors had decided to move. We, my wife and I, purchased the home next door to us. We moved my mother and father to Charleston, so that I would be closer and able to lend the care that was needed. Needless to say, this put a financial strain on us, until last month I was making three mortgage payments. Thankfully, we were finally able, last month, to sell the house in Elinor, which has allowed us to pay off one of our mortgages.

My wife has a good job, and that certainly helps, but we have a 17-year-old son and have to assist my parents. They get a Social Security check and they also receive an income from property that they own, but it isn't enough to cover all of the costs including: the medication bills that reach $150 a month; special equipment, like bathroom rails and seats, that exceed $200, that are not covered by Medicare.

My father's disease and the cost of his care has forced us to change our entire lifestyle, and makes it so plans which we once had cannot be completed. I am a family-oriented man, and we always did things together as a family. Now, we can't even consider a vacation. We had hopes that we could send our son to college. We may very well have to use his education money for the care of my father. If he can go to school at all, our ideas are: it will have to be a local college; he will live at home; and he will help pay his own way through school by working.

My mother is at my father's side every moment. I run some of their errands, and sometimes relieve my mother so that she can get out of the house. Just yesterday she asked when I would have time to relieve her long enough for her to go Christmas shopping.

My mother is very clear and very definite: She does not want my father in a nursing home. Her exact words were: "I will be dead before that trip is made."

I want to honor my mother's wishes. We all want my father to stay at home, but it is hard to do. It is very difficult to find affordable home health care. I have talked with my wife about the possibility of quitting my own job to help take care of my father, but I don't know how we could exist on just my wife's salary.

We have looked into other options like getting someone to move into the house to help with the care, but they want a salary plus room and board. This turns out to be very expensive. The other day a doctor examining my father asked if he ever got violent, or if he had ever wandered off. My mother's answer to both of these questions were: "No."

With a surprise look on his face, the doctor looked at her and said: "Mrs. Keeney, you can be honest with me."

She again looked at him and said: "No."

His remark was: "It is surprising what a little love can do."

My family comes in every day to touch, embrace, and make my father feel loved. I think his being at home makes a big difference, but it could ruin our families financially.

My mother and father both worked hard all their lives and went through the Depression. They are proud people, yet just the other day my mother said she was worried about being left with enough money to have a proper burial.

My support comes from belonging to the Alzheimer's Support Group, here in Charleston, where we all gather and discuss what our loved ones are going through, and what we can expect in the future. We are a group of caregivers, but I call our group a group of victims. My father may be the patient, but my mother is the victim.

It is hard enough dealing with my father's disease on an emotional level. It should not also come to us the anguish of financial disaster. We must do something to allow our loved ones to stay at home. I feel that a tax deduction for long-term care families, might be of some help. A Social Security withholding, which would assist all type of long-care illnesses, might be another possible answer. At any rate, we need a complete solution to this long-term care crisis now.

Another big need is facilities and trained staff or trained volunteers to provide respite care which allows the caregiver time for him or her to get a break from the 24-hour-a-day care of their family members. An example would be a day care center for those patients that are mobile. However, many patients are not mobile, and are confined at home. The caregiver is, at that time, in a situation especially in need of break for their own emotional and physical well-being.

As I mentioned before, paying affordable home health care becomes financially burdensome to senior citizens on a fixed income as well as all long-term families. One of the slogans, Senator, in my business is that we have all the right parts in all the right places. It is my prayer that, Senator Rockefeller, that you will be in that case when you and your colleagues in Congress meet to address this crisis.

Thank you for the opportunity to share my story and the story of millions of others. [Applause.]

Chairman ROCKEFELLER. Thank you, Mr. Keeney. Thank you, as I thanked Debbie, for your extremely open and candid way of talking about these things. It is extremely hard to talk about your situation openly to other people. But, on the other hand, other people don't know what people, like your families, are going through. They just don't know and that's why a hearing like this is important—where even though it is uncomfortable for you to talk, to let people know, to go on the public record, with your stories is so incredibly meaningful. You are doing your State and the whole country a big service.

Rev. Oakes, sir, we would be delighted to hear from you.

STATEMENT OF REV. DANIEL E. OAKES, CHARLESTON, WV

Reverend OAKES. Thank you, Senator Rockefeller. It is a real privilege, ladies and gentlemen, to be here. Folks, I was a chaplain

in the U.S. Air Force. My job was to take the bodies of the ones of those who had been killed to the place where they had to be buried. Senator Rockefeller, I laid to rest hundreds of my brothers that fought in Vietnam, but I have never had anything so devastating happen to me as when they told me my wife had cancer, and that she could die.

Let me share with you. In December 1988, I was unemployed and unable to find a job in West Virginia. Since I am a golf teacher, I decided to take my family to Myrtle Beach, SC. I had inquired with people that I knew, and they said: "There is work down here for what you can do, so come on, we'll help you find a job."

Although we did not know, at that time, any possibility that my wife would have cancer, her symptoms turned out to be uterine and cervical cancer.

She had no menstrual periods for a long time, and when she did, it was abnormal bleeding. She went to a number of doctors and physicians within the Charleston area, and they told us that it was because of her weight.

A woman knows her body. I cannot tell you as a man, actually, what a woman would experience in a situation like that. I'm safe in saying that a doctor who is a man couldn't express that either. I've never given birth to a child. I do know in my heart that she knew something was wrong, something was bad wrong.

Because of the abnormal bleeding, Senator Rockefeller, and the unusual pain she was having, it was extremely difficult for me to maintain a job.

When my wife went to the hospital, I was working for a company named American General Life & Accident Co. Because of my life situation, I was unable to perform the duties to my capacity. I say this in humility; I am a professional. I know how to sell. In 6 years, in the 1970's, I sold $39 million of life insurance in the coal fields, because I love people who need help.

When this insurance company found out my wife had cancer, they fired me. Now sir, I can't prove this in a legal way, I'm not an attorney, but unofficially the manager of that insurance company told me: "Son, you'll never make it here, because you're wife is not going to drain this company, because of a catastrophic illness."

You see, Senator, I couldn't perform the job in a complete way with my wife having all of these problems. The very day that the doctor had come in, and they found—from pathology and cytology, from the endometriobiopsy after they did the first surgery—that the problem was a malignancy, that was the same day the man told me: "Unless you come in and meet with this office meeting in the morning, you'll be fired."

So, sir, I went. I went to the office and I was there for the meeting. When I turned in my report, the manager walked out of the office and said: "Dan, you're fired."

My wife was in the hospital, and we didn't know yet that she had cancer, because the reports had not come back. When I went to the hospital to see her, I was so hurt and torn up, because I wanted to tell her that everything was OK, but I had been fired. I left, but she knew something was wrong, Senator Rockefeller—and you know a wife knows her husband better than anybody. Because of the stress, and the tremendous amount of anxiety, frustration, and

tremendous pressure, her blood pressure went to 280 over 230 that evening. She knew. I didn't have to say I was fired. She knew. At the same time, the oncologist came in and said: "Mrs. Oakes, we did find cancer"—very bluntly. "These are the options. We can give you radiation, which may cause a hole in your bladder, which would cause the problem that we would have to do a colostomy, which may be irreversible."

Senator Rockefeller, I took what little bit of money I had to go buy some gasoline and siphon the gasoline I had out of my lawnmower to put in a 10-year-old car to go to the welfare office. Sir, when I got there, I was treated like a second-class citizen. I waited 7 hours in that office, and they told me they couldn't see me. I would have to come back. I went back, because I learned a long time ago that inspiration and perspiration is the secret of success.

I was going to talk to somebody to get help. I determined in my heart that I would stay there as long as it took. I went back.

Because I was out of work, my utilities were being cut off. I was broke. I was so far down below bottom, sir, I had to look up to see bottom. That was worse than Vietnam, because I didn't know how to cope with it. Then I found out my wife had cancer. That's the straw that broke the camel's back.

When I went to the welfare office—I went out there and my wife was still in the hospital. This was after the second surgery. They went back in, less than a month later, sir, they reopened the same incision only 2 inches wider on each side. They opened her all the way up to do an exploratory. They examined everything: her spleen, her liver, her kidneys, her bladder, did it all to make sure there was no more cancer.

When they put the saline solution in and sent it to pathology, and got the report back, thank God, it was negative.

AUDIENCE. Thank God.

Reverend OAKES. Our burden and our nightmare was not over, sir. I knew in my heart that the Lord had showed me that the truth was a matter to seek until I got every answer I needed.

They told her, there was two schools of thought. She could go through extensive radiation that would require 25 through 28 treatments. I have had a lot of cancer people in my family. She's the first in her family. She said: "Dan, I can't put our children through it."

The other option was to go in the hospital, have an insertion into the vagina, and they put radioactive material into that insertion. She would be on her back 3½ to 4 days, maybe more. So they put her in the hospital here, sir. They did that procedure. Still yet I had no medical insurance. I have a bill right here for the surgery of over $5,000. American General says they are not going to pay it.

The welfare never gave me a medical card, sir, until my wife was coming out of the hospital, after the procedure was over. The only reason I got it, Senator Rockefeller, was because a lady named Catherine Carns, a social worker here at the hospital, had the insight and the power to make the wheels turn. She knows and she believes in what's right.

My wife had had two surgeries within 30 days. After the second surgery her incision completely opened up, sir. She hemorrhaged, she almost died. She was covered with blood. I got her to the hospi-

tal—I live 15 miles from this Women's and Children's Hospital. It took me 7 minutes to get her to the hospital. I couldn't wait.

You see the thing of it is, sir, and I say it with love in my heart, down at the welfare office, those social workers are quitting because the Governors have cut their salaries back to where they are on minimal income. The man goes in office and promises—and I supported him with all my heart. I stood in line behind a lady at Kroger's last night, who spent $300 of her miner's pension check to feed four people in her family. She is a widow. She had to pay $18 tax on her food. Why don't they tax cigarettes and booze?

AUDIENCE. Yeah. All right.

Reverend OAKES. I say that with love and respect, sir. The common people are tired of paying the price. I know in my heart, without any question of a doubt, if there is a way, you'll find it.

When I took her back home, we found out that a staff infection had set in on that open incision—the fourth time she had to go back to the hospital for a number of days. They didn't know exactly what was wrong. They thought maybe it was a flu virus, cause it was going around. It wasn't a flu virus. It was an infection, a staff infection, which is a common happening.

I took her back home, sir, she was scheduled to go in within just a short time for the radiation therapy. The doctor had scheduled her to go into this hospital. We go back, we're ready, had the suitcase packed and everything. We go in, and the nurse says: "No, they rescheduled you."

I found out it was because another lady in front of us had medical insurance and we didn't. They hadn't given me the medical card yet. They put Sharon on a medication called Medgay [phonetic], sir, which cost $97 just for 20-some pills, plus 4 or 5 other prescriptions. There was no way for me to pay for it.

Again, I go to Mrs. Carns, and she said: "Danny, the hospital will supply it while she is in the hospital. I'll see to it that you get a medical card."

Senator Rockefeller, my wife didn't have the surgery she needed, that would have made it easy on her. They took her down to the doctor's office, and gave her a local anaesthetic. My wife felt everything that happened when they inserted it into her. She cried her heart out in total pain. All because we belong to a system that would not fail. But it did fail.

I went back out to welfare and I said: "We need help. I've got to have some food stamps and some money to pay these utilities."

They said: "Well, your wife is not home yet, so we'll have to wait for her to come in and sign the papers."

I said: "Mister, my wife has been in the hospital four times. She can barely walk, much less sign papers."

If it hadn't been for the American Cancer Society, there was no way that I could have got gauze, saline solution, and water—pure water—to clean the dressings on her open incision. The American Cancer Society came through when the welfare wouldn't.

Sir, I went out there, and I sat for 7½ different days to get benefits. I guess they got tired of looking at me, because they knew I wouldn't leave. In the 7 days, I had 9 different social workers, and I had to go through the whole thing again with them. Finally, we got our welfare check for $312 a month.

Back in December of last year, I had to go on welfare because there was no work here.

Now I've got to try to support 4 people on $280 a month. They haven't sent any food stamps this month at all. I called out there the other day, yesterday, to tell them, and this is the note that Mr. Hawk, who is now my social worker—I've never heard of him. He told me that my benefits have not been returned. Well now, who is going to return food stamps to the welfare office, if they are hurting, and they know they can spend them without any detection?

So you see, here it is Christmas. Every utility I've got at home has a shutoff notice on it. I have no food stamps to buy food. We do have a medical card, but, I don't know where the end of it is. I've done everything I know in my heart. I've been truthful. I've been diplomatic. I've been sincere. I haven't held or reserved anything.

God bless you. I appreciate it. [Applause.]

[The prepared statement of Rev. Oakes follows:]

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TESTIMONY OF

REVEREND DANIEL EDWARD OAKES

CHARLESTON, WEST VIRGINIA

BEFORE THE PEPPER COMMISSION

DECEMBER 13, 1989

For further information, please contact:
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Good morning, Senator Rockefeller and members of the Commission. My name is Reverend Daniel Edward Oakes and I live here in Charleston, West Virginia. Because of the job shortage in West Virginia, I have gone from job to job over the past several years, and I am currently unemployed. I am 43 years old and my wife is 35. We have two children, ages 13 and 11. My family's nightmare with America's health care system began last year when my wife Sharon developed symptoms of uterine cancer.

In December 1988, I was unemployed and unable to find a job in West Virginia. Since I am a golf teacher, I decided to take my family to Myrtle Beach, South Carolina to try to find a job teaching golf during the season there. While we were in Myrtle Beach, my wife became ill. Although we did not know what was wrong at the time, her symptoms turned out to be those of uterine cancer -- including no menstrual periods, abnormal bleeding and severe pain. Because she was ill, she and the children returned to West Virginia so she could seek treatment, but I remained in Myrtle Beach so I could continue to work.

After returning home, Sharon went to several doctors to find out what was wrong. All of the doctors she saw told her that her problems were a result of being overweight. None of the doctors suggested that it might be cancer.

Sharon, of course, knew that her problems were more serious than weight, be she did not know what to do.

By April of this year, Sharon was getting much sicker, and since the season was over in Myrtle Beach and there was little work for me there, I returned to West Virginia to try to find another job. After working for brief periods for two companies, I began working for American General Insurance Company, where my benefits included health insurance. At this time, Sharon's condition was getting worse, but still had not been diagnosed. Throughout the spring and summer, I needed to take time off from work so that I could take care of Sharon.

Sharon's doctors decided to operate in August to remove her uterus and part of her cervix. At this time, one of her fallopian tubes ruptured, and this was removed also. After the surgery, the doctors were finally able to make a diagnosis -- adenocarcinoma, or tumors of the uterus.

I took the days before the surgery off from work so I could be with Sharon at the hospital. I had also planned to be at the hospital on the day of the operation, but my employer informed me that if I did not show up for work I would be fired. So while Sharon had surgery, I went to work. When I got to the office, I was fired. The "official" reason was that I was not productive, but how

could I be productive at work when my wife was unable to take care of herself at home? However, I believe that the real reason I was fired was because my wife had been diagnosed as having cancer. My manager told me "unofficially" that they would not let me milk the company dry with my wife's health claims. So just when I needed it most, I lost my job, and with it, my health insurance.

Sharon was operated on again in September. This time her ovaries and her other fallopian tube were removed. I was still unemployed, and unable to pay my bills, so I applied for welfare, but I was told that my application could not be processed until my wife came to the Welfare office to sign the papers. Sharon, at the time, was in the hospital having surgery. In desperation, I asked everyone I could think of to help me pay my bills. The Salvation Army paid my water bill, and my Methodist pastor raised money to pay the electric and gas bills. But I still had no money for food or for Sharon's medical bills, which included $400 - $500 a month in medication. Since I had no health insurance, Sharon could not remain in the hospital, so she came home and I took care of her and changed her dressings myself.

In October, Sharon's medication ran out and we had no money to replace it. Her doctors had also decided that the best follow-up treatment for her would be a radiation

implant. When Sharon went back into the hospital for the implant in October, a hospital social worker called the Department of Human Services and insisted that our welfare application be processed so that we could get a Medicaid card. This was over a month since I had first applied. Normally, radiation implants are inserted surgically under general anesthesia. However, when the doctor saw that we had a Medicaid card instead of private insurance, he took her into an examination room, gave her a local anesthesia and inserted the implant. As you can imagine, this was unnecessarily painful for Sharon, and she still has not recovered from the procedure. In addition to the severe pain that Sharon is suffering now, one of the drugs she is taking seems to be causing a film over her eyes which is blocking her vision. We went to see an optometrist about this, but he does not accept Medicaid as payment.

With the help of the hospital social worker, I finally started receiving welfare assistance. However, last month the Department of Human Services realized that in February of this year, I had received a settlement of approximately $5000 as compensation for an injury I suffered last year. When I first applied for welfare, I told them about this settlement and they told me not to worry about it. Now they are telling me that this settlement is counted as income and that I am no longer eligible for welfare. This month I received a welfare check for $312, but no food stamps. For

a family of four, $312 will not even pay for my utilities, let alone food and Sharon's medication.

Senator Rockefeller, I am a college graduate, and I served my country during the Vietnam War. Now I am treated as a second-class citizen because I am unable to pay for needed health care for my family. Although my wife's surgeons and the hospital have been wonderful, the West Virginia Department of Human Services has given me the run-around every step of the way, when all I want is to get my wife the proper medical treatment. In a nation so full of resources, I am constantly amazed that an honest, hard working individual like myself is unable to access the system.

Chairman ROCKEFELLER. You know I had a number of questions that I was going to ask each of you, but I think your testimony is so eloquent and so deep, that I think it is just better that we leave it right there. If I feel that later on I should come back with a question for any of the three of you, can I feel free to do so?

Reverend OAKES. Absolutely.

Chairman ROCKEFELLER. I could write or even telephone you, too. I really thank you for coming in. Each of you, in different ways, have expressed agonies which are powerful, and unfortunately, all too common. Not only in West Virginia, but in our country. I really thank you for coming. Thank you very much. [Applause.]

Our second panel will look at these various problems from a national perspective. Dr. Harold P. Freeman is president of the American Cancer Society—and Reverend Oakes just said some pretty good things about the American Cancer Society. He is accompanied by Joan Ross, whom I have known for years, from Huntington, WV; and then James Sykes, from the University of Wisconsin, who is chairman of the Public Policy Commission of the National Council on Aging.

Dr. Freeman, maybe we'd start with you, sir. We thank you very, very much for being here.

STATEMENT OF DR. HAROLD P. FREEMAN, PRESIDENT, AMERICAN CANCER SOCIETY

Dr. FREEMAN. Thank you very much, Senator.

It is a great privilege for me to be here and to represent the American Cancer Society. I am a surgeon who has practiced for 22 years in the community of Harlem in New York City. This is one of the poorest communities in the country and it is a community which reflects what happens in poor communities all over the Nation, including the ones here in this State, in this city.

I had an opportunity to have firsthand experience at what happens to poor people who develop cancer, because cancer is the field that I am trained in. When I first came to Harlem I immediately realized that in Harlem I was seeing very advanced disease, and that the people were dying at a much higher rate. This stimulated me to think more deeply. In the last 22 years since I've been in Harlem, I've had the opportunity—through my work with the Cancer Society—to understand how the Harlem problems apply to the whole American society. In other words, I think that the health problems that we see in Harlem are very similar to health problems experienced by other poor Americans including those in this city and elsewhere.

Cancer, indeed, is a very liberal disease, Senator. It affects all of us. It is estimated that 30 percent of the American population will have cancer, will experience cancer individually, at some time in their lives. Three out of four of our families will have a member with cancer. Cancer is a disease that affects everybody in a liberal way, but the society in which we live in seems very conservative in confronting the disease, as it is conservative in confronting many diseases that affect people.

President Nixon declared a war against cancer in 1971. The result of that is we spent many research dollars in cancer and cur-

rently the budget of the National Cancer Institute is $1.6 billion. This is very fine, because I think that the final answers to the cancer problem will be based on research results.

What I am thinking now, Senator, is that we have to declare a new kind of war against cancer, a war that affects people individually where they live, a war in their own neighborhoods. That I would call more of a guerrilla war. We have failed in that war against cancer.

We have a crisis in the country now. Cancer is one reflection of that crisis, but it is a very significant reflection because cancer is the No. 2 leading cause of death in American people. One million Americans develop cancer each year, and one-half million die from it. A disproportionate number of these people are people who are poor and disadvantaged and uninsured.

The statistics indicate that there are currently 34 million American people of all races, living below the poverty line, which is approximately $12,000 a year for a family of four. Only 45 percent of those people who are designated as poor are considered poor enough to receive medical assistance, in the form of Medicaid. So more than half of those people are not poor enough to receive Medicaid, too rich for Medicaid, but yet too poor for Blue Cross and Blue Shield—a very devastating problem.

In addition to that, as you have stated in your opening remarks, there are 37 million American people who have no health insurance. These people overlap the poor in such a way that there are 20 million of the uninsured who live above the poverty line, but are not far from it.

This also is a devastating problem. When you add up the poor with the uninsured, it reaches the level of an estimated 55 million American people who either are poor or insured, or a combination of both. All of these people have a very, very difficult problem in receiving health care, especially for a lethal disease such as cancer, which must be diagnosed early in order to afford a chance for cure.

Poor people in general receive care on an episodic basis—going into an emergency room, when they have real symptoms. Cancer is a disease that—when it is diagnosable and treatable early—it is very subtle. People need to come in quite early to be screened and diagnosed for various minimal symptoms to be afforded cure.

The system drives poor people to come in with late disease. In fact, we found that the bureaucracy of this system is so intense, and the barriers are so great, that people consider a painless lump in the breast—which may be cancer, and may ultimately kill the person—to be less severe and less painful than the process of getting into this very difficult bureaucracy that we call the American health care system. This is, in a nutshell, part of the problem.

We conducted seven hearings across this country. The American Cancer Society went to seven American cities throughout the country including: Jackson, MS; Atlanta, GA; Newark, NJ; St. Louis, MO; El Paso, TX; Sacramento, CA; and Phoenix, AZ. On behalf of the Cancer Society as president I reported the findings of these hearings to Members of Congress, the White House, and the American public in July 1989. The purpose of these hearings, Senator, was to hear directly from poor people what their own experience was when they developed cancer. I tell you this was one of the

most moving and compelling experiences that I personally have ever experienced.

They told us that they did not have access to health care. They told us of the barriers that they were confronted by in trying to get into this system: sometimes having to go to four or five different parts of the city—at a point where they had no money for cabfare or carfare, to get to those places—in order to be confronted with indifferent people who told them to wait for several hours, as Reverend Oakes has told us today he had to wait. Stories like that were very abundant.

They told us that the educational system that we have in America is basically insensitive to their needs and irrelevant to their concerns. The language being used to communicate to the American people does not reach nearly all of its people. There is a need to change this language to make it sensitive to people who can hear the language in their own terms.

They told us that they endure greater pain and suffering from a disease such as cancer—which is reflective of all diseases they endure—because they come in late, and they have a lower quality of life. They indicated that they make extraordinary sacrifices: sometimes losing their jobs; losing homes; and worst, perhaps, of all, losing their dignity. There were many people that told us how they lost their dignity in this process.

We had one 32-year-old woman, a white woman from Colorado, who developed breast cancer. She told us she was uninsured. She was fighting the system. She had to have a mastectomy and other treatment. At one point she said to us: "You know, I'm having more trouble fighting the system than I am fighting my disease." That was how she saw it.

Poor people develop fatalism. The fatalism is well-founded because they see people around them—their families, their friends—who have tried to get into the system and failed. People who have died and have developed serious diseases while waiting to be treated, in a system that doesn't handle these things very well.

I would say that we have a very, very significant problem—particularly with respect to cancer. In a way, I see it as a kind of an American dilemma. We are in a country which has developed, perhaps, the highest technology in science that has been seen in the world. Our technology has really outstripped our humanity, because it really isn't even really American to see the pain and suffering in this country—from America's poor of all races—a country that has such abundance.

I think that we have shown that a major determinant of cancer death is related to the circumstances that people live within—poverty being the underlining factor, because poverty is a proxy for many negative events that happen in the course of human life. Poor people tend to be less educated. Poor people tend to be more often unemployed. Poor people have less access to the health care system. Poor people have poor nutrition. They have a sense of isolation and powerlessness. They confront barriers in getting into the system. These are the problems that we are facing in the poor and in the uninsured.

I see that we have an opportunity as well as a crisis, Senator, in this fight. I am very happy that the Pepper Commission is in exist-

ence, and that you in particular are the chairman, because I know who you are, and I know your background. I feel very good to have you in this kind of a position: as chairman of this committee.

I think that there may be many approaches to change this. We cannot go on like this. It is just a matter of time before the system will fail even more miserably. As we see the circle of poverty getting larger, we see the middle class having these same problems as the problem expands. There are people becoming poor when they lose their jobs, every day. The circle of poverty is not a closed circle. People who are middle class today may be poor tomorrow.

It is a problem we have to confront as an American problem, regardless of whether you are middle class now, or poor, regardless of whether you are white or black, regardless of what your circumstances are. It is an American problem that involves all of us, and all of us must fight it and face it.

Chairman ROCKEFELLER. Dr. Freeman, I hate to do this, but I am going to have to ask you to wind up fairly quickly.

Dr. FREEMAN. That I will do. I think that there are three major approaches which I would recommend to this problem, from the point of view of the American Cancer Society. We need to create a medical care system that is friendly to all of its users. It is really devastating to have a system that does not admit all people, regardless of their ability to pay, particularly with respect to a lethal disease such as cancer. We need to change our educational system to be sensitive to all people, the language of all people. We need to create a system to navigate people through the bureaucracy and eliminate the bureaucracy.

In a way, it is like the *Titantic,* Senator. Rearranging the furniture on the *Titanic* would not have averted the catastrophe. They would have had to rechart the course. And that Senator is what we have to do with the American health care system.

Martin Luther King said: "Of all of the inequalities, injustice in health is the most shocking and the most inhumane."

Thank you, Senator. [Applause.]

[The prepared statement of Dr. Freeman follows:]

AMERICAN CANCER SOCIETY

TESTIMONY OF

HAROLD P. FREEMAN, M.D.

DIRECTOR OF SURGERY,
HARLEM HOSPITAL CENTER, NEW YORK

IMMEDIATE PAST PRESIDENT
AMERICAN CANCER SOCIETY

ON BEHALF OF THE

AMERICAN CANCER SOCIETY

BEFORE THE PEPPER COMMISSION

CHARLESTON, WEST VIRGINIA

DECEMBER 13, 1989

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Good morning Senator Rockefeller and distinguished members of the Pepper Commission. My name is Harold P. Freeman, M.D. and I am Director of Surgery at Harlem Hospital Center in New York and the Immediate Past President of the American Cancer Society. The American Cancer Society (ACS) is the national voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives from cancer and diminishing suffering from cancer through research, education and service.

A major ACS priority has been improving access to cancer care for those people who are at greatest risk of dying from cancer -- the poor. The Pepper Commission is to be commended for its work in identifying and bringing to the public's attention the lack of quality health care in the United States for those without health insurance or with inadequate health insurance. I am pleased to have the opportunity to bring the Commission some insights into the problems related to cancer in the poor.

The American Cancer Society has long been interested in cancer incidence and mortality among different ethnic and socio-economic groups. In the 1970's we focused on cancer mortality rates among different races or ethnic groups. Three separate surveys by the National Cancer Institute (NCI) in 1944, 1959 and 1971, and an historic report in 1972 by Howard University all documented a high cancer mortality rate in black Americans as

compared to white Americans. In 1972, a larger program by the NCI, gathering data from 11 population-based registries was begun. This program, called SEER (Surveillance, Epidemiology, and End Results), gave information on cancer incidence and mortality in the United States from 1973-1981 and presented the first detailed data on occurrence of cancer among native Americans, Hispanics, Filipinos, Chinese and Japanese, black and white Americans. Previously, data by race/ethnicity had been available only for black and white Americans.

In 1979, I presented a report at the American Cancer Society's Science Writers' Seminar regarding the diagnosis and treatment of cancer at Harlem Hospital. What I found was that half of the 165 consecutive patients with breast cancer seen at Harlem were incurable on admission. All of these patients were black and poor. The five-year cure rate was 20% compared to 65% found in white American women. Poor patients, not able to pay for medical care by a private physician under our fee-for-service medical system, are frequently seen first in an emergency room and referred to a clinic. Long waiting periods and complex registration procedures discouraged patients from going through this process and the result is often late diagnosis at an incurable stage of disease.

We began to compile more statistics from patients at hospitals and from other sources around the country that indicated

that economic status is the major determinant of the poor survival of black Americans with cancer compared to white Americans and is probably a major factor in cancer survival for American people as a whole. In response to this information, the American Cancer Society took on a new minority outreach initiative to take cancer prevention and detection into all the nation's neighborhoods. Throughout the early part of the 1980's the American Cancer Society continued to compile information about cancer incidence and mortality and lifestyle choices of minority groups.

In 1984, the ACS Board of Directors approved the formation of a special subcommittee on Cancer in the Economically Disadvantaged. The new committee would examine in depth the influences of socioeconomic status (SES) and its implications for action by the ACS relative to the risk of developing cancer, promptness in obtaining diagnosis, access to availability of and adequacy of medical care, and other factors that contribute to cancer incidence, lower survival rates and mortality. A study was commissioned to research the data relating racial and socioeconomic factors with cancer incidence and survival and to consider possible causal mechanisms involved in differences noted in survival rates. A major question to be explored was the extent to which economic status accounts for the differences in survival and mortality between racial groups.

The findings from this report and other supplementary data relating to cancer incidence and survival was presented to the American Cancer Society's Board of Directors in 1986 in a "Report on Cancer in the Socio-Economically Disadvantaged." The following major findings were reported.

- In the studies that have considered socioeconomic status (SES) and ethnic differences together (most based on black/white comparison), controlling for SES greatly reduces (and sometimes nearly eliminates) the apparent mortality and incidence disparities between ethnic groups. This suggests that ethnic differences in cancer are largely secondary to socioeconomic factors and associated processes.

- There are consistent excesses of cancer mortality overall and cancer mortality for many specific sites for patients of low SES compared to high SES.

- These group differences are functions either of differences in incidence rates, or in relative survival rates (or both) with proportional influence differing by sites. The economically disadvantaged have higher incidences for several sites and lower survival ratios for all sites combined.

- Estimates suggest that at least 50% of the survival differential is due to late diagnosis in the economically

disadvantaged supporting a major role for early detection programs and access to treatment for the poor.

- Overall cancer mortality has declined slightly for females and increased substantially for males over the past 30 years. The highest rate of increase has been among black American males, probably because of the disproportionate number of the black American population in the low SES categories.

- Certain risk factors, behavior, dietary practices, and occupational exposures appear to be related to excess cancer incidence and mortality among economically disadvantaged persons.

- Worst differences -- both psychosocial and biological -- possibly associated with nutrition, immunity, or environmental factors adversely affecting the disease process are contributory to lower relative survival rates among economically disadvantaged persons.

- More information is needed on nutritional factors as they relate to cancer survival. For example, are lower socioeconomic patients already compromised because of inadequate nutrition? This may have implications for the types of management that would be most effective.

- Evidence from ACS and other studies have suggested certain public myths about cancer that hamper the effective use of early detection programs have been documented.

- Even with improved access to health care providers, there is statistical evidence of fewer prevention type services. Patient compliance, i.e., the understanding of prevention focus procedures, adherence to treatment protocol and follow-up visits seem to be a particular problem for economically disadvantaged persons.

The findings cited in this report suggest the necessity for a major effort of government, private and voluntary sectors to bring about changes in the nation's health care system to address the disproportionate cancer incidence and mortality among the economically disadvantaged.

To better understand the dimensions of this problem and to identify possible solutions, the American Cancer Society sponsored a series of hearings across the country in May and June 1989 with the cooperation of the National Cancer Institute and the Centers for Disease Control. These hearings are part of a special ACS initiative to serve the disadvantaged.

Sixty-eight disadvantaged people and 94 professionals who work with the disadvantaged presented testimony at seven regional

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hearings. We also accepted written or video testimony from 76 individuals who were unable to participate. Hearings were held in Atlanta, GA; Jackson, MS; Newark, NJ; St. Louis, MO; El Paso, TX; Sacramento, CA; and Phoenix, AZ. People from throughout these regions presented testimony, with 47 states and territories represented. The findings of these hearings were presented to Members of Congress, administrative officials and the public at a "Report to the Nation" in Washington, D.C. on July 17.

The series of hearings were some of the most moving, informative, and heartwarming experiences of my entire career. Representatives of the socioeconomically disadvantaged themselves, and other groups and agencies, brought to the nation's attention the need to improve on the availability and the access to health care for all of the people in America, regardless of their ability to pay.

I would like to share with you briefly, the major findings of the hearings report.

o Poor people lack access to quality health care, and are more likely than others to die of cancer.

This statement represents a truism that is supported by the following major findings in the report.

o Poor people endure greater pain and suffering from cancer than other Americans.

There is substantial evidence that the poor are more likely to be diagnosed with cancer when the disease is more advanced and the treatment options are significantly more limited. In addition, poor patients are forced to accept substandard treatment and to endure assaults on their dignity to obtain needed care.

o Poor people face substantial obstacles in obtaining and using health insurance and often do not seek needed care if they cannot pay for it.

At least 31 million poor and near poor Americans cannot afford private health insurance and are ineligible for public assistance such as Medicaid or Social Security Disability benefits. Those who are insured are often financially devastated by the substantial gaps in coverage. Delays in eligibility, and bureaucratic snags in processing claims, cause poor patients to suffer added hardships. Instead of battling the disease, many poor patients find themselves battling the whole system, trying to figure out what to do and how.

o Poor people and their families must make extraordinary personal sacrifices to obtain and pay for health care and

many poor Americans are forced to choose between paying for food and shelter and paying for care.

To find and pay for cancer treatment for themselves or their family members, poor Americans may sacrifice their homes, their jobs, and even their families. Cancer drives many middle-class people into poverty -- in other words, the disease itself may be impoverishing.

o Cancer education and outreach efforts are insensitive and irrelevant to many poor people.

The burden of daily survival weights heavily on the poor, and health concerns are often ignored until pain is significant. Cancer education efforts often ignore this reality and are thus largely irrelevant. This problem is compounded by the lack of educational materials which appeal to different cultures and a lack of volunteers in poor communities. A quote from a woman from Trinidad, California points to problems in reaching the poor with educational messages about cancer. "If I knew what I know now, I could have questioned their diagnosis. If I had known, if I had had more information, I could have gotten to a specialist two or three years earlier than I did. And it probably would have made a difference."

- Fatalism about cancer prevails among the poor and prevents them from gaining quality health care.

Based both on limited knowledge and on the reality of their encounters with the health care system, poor Americans mistakenly believe that there is no hope of surviving cancer. Fears and misperceptions about cancer prevent many poor Americans from seeking needed care. Joan Ross, the Executive Director of the Southwestern Community Action Project in Huntington, West Virginia summed it up neatly. "People avert their heads, lower their voices...it is a sentence to die."

Mr. Chairman, these major findings represent gaps in health care that must be addressed by all sectors of American society. The American Cancer Society has identified a number of challenges to meeting the cancer control needs of the poor and will work with federal, state and local governments and business, health, insurance, community action and special interest groups in the private sector to accomplish these goals. Briefly, these goals are:

- Assure that cancer prevention, detection, treatment and rehabilitation services are available and accessible to all who need them, regardless of the ability to pay.

- Improve cancer prevention and early detection among poor Americans to eliminate unnecessary pain, suffering, and death.

- Undertake aggressive educational efforts to counteract fatalism, overcome fears and enable poor people to reduce cancer risk.

- Develop cancer education materials and outreach programs which are culturally sensitive, understandable and relevant to poor people.

- Establish patient advocates and referral services to help poor patients navigate the health care system and manage personal problems which results from cancer detection and subsequent treatment.

- Involve community organizations in serving the poor and poor people themselves in cancer education and patient advocacy programs.

- Train health care providers to be more sensitive and understanding of the needs of poor patients and to better serve their needs.

- Expand availability of and accessibility to health services for poor people in all areas which are now underserved.

- Conduct research to further document the scope of the problem and identify effective interventions.

The American Cancer Society is committed to addressing the needs of economically disadvantaged Americans, and has launched a number of innovative programs to serve this population, including $1.8 million in demonstration projects in three communities -- Miami (FL), Oakland (CA) and Harlem (NY) -- on cancer early detection, prevention and education. We are using the findings of these hearings along with other research to further develop specific programs and policy positions which will respond to the challenges I have just outlined.

Thank you for allowing me to be here this morning. On behalf of the American Cancer Society, I look forward to working with you and other distinguished members of Congress to address the problems of access to health care for the 34 million economically disadvantaged Americans. I mentioned that Joan Ross of the Southwestern Community Action Center in Huntington is here with me today. Ms. Ross testified at our hearing in Atlanta, Georgia. We would be happy to answer any questions you may have on the findings, and problems specific to West Virginia.

Chairman ROCKEFELLER. Thank you, Dr. Freeman. Is it Jim Sykes or James Sykes?

Mr. SYKES. Jim.

Chairman ROCKEFELLER. Jim Sykes. We are awfully glad you are here, sir.

STATEMENT OF JAMES T. SYKES, UNIVERSITY OF WISCONSIN-MADISON; CHAIRMAN, PUBLIC POLICY COMMITTEE, NATIONAL COUNCIL ON THE AGING [NCOA]

Mr. SYKES. Thank you very much, Senator, and we are delighted to be here. As chair of the National Council on the Aging's Public Policy Committee; the founder of a successful community-based long-term care system in Wisconsin; and as a teacher at the medical school at the University of Wisconsin, I have witnessed the need for a national policy on long-term care, which insures that persons of every age have access to comprehensive, affordable, quality care. Stopgap measures, tinkering with Medicare or Medicaid, to add limited services with minimal funds, simply will not do.

The mandate of this Commission demands a dramatically new approach to health care in America, especially for those who face double jeopardy: serious illness and impoverishment due to health care costs.

The Nation is poorly served by a system that works for some, but not others; covers certain illnesses, but not others; and provides options for some, but institutionalization and impoverishment to others. Benign neglect and overreliance on a patchwork system of private, out-of-pocket spending, and Medicaid, must be replaced by a comprehensive, national health care system.

Repeatedly, polls have shown that we want a sensible, affordable, quality health care system. Those same polls show we are willing to pay for it through our taxes.

I would like to draw your attention to three problems calling out for solution. First, we need to build a service infrastructure in neighborhoods and communities to provide options and support to vulnerable individuals and their families. Second, we need to enable elders to continue to live where they prefer, in special places: elderly housing; group homes; continuing care; retirement communities; and naturally occurring retirement communities. Third, we need to recruit and train professionals, managers, chronic care workers, and volunteers, to provide the care and support essential to a health care system that works for all. Only within the framework of a national health care system can these and countless other problems be properly addressed.

Care should be delivered to where one lives, not the other way around with the ill transferred to facilitate providers or to simplify administrative process. Attention must be given to both the one directly in need of intervention and support, and, as we have heard this morning, the providers of care. The individual must be at the center of every care plan, controlling and sharing responsibility for his or her care.

A national policy must be grounded on principles. In my text, I have listed 11 principles for your consideration.

To address the first problem, building community services to care for those able, with help, to remain in their homes, let me mention Wisconsin's Community Options Program, a program that works. A Commission study on the Community Options Program will offer evidence that providing appropriate services to individuals in their homes, and support to their care providers, is not only effective and humane, but also less costly than institutional care for the overwhelming majority of persons served.

Service providers and care managers are available in many Wisconsin communities because a revenue stream is assured: Funding follows the individual.

In Wisconsin, a sum equal to about 60 percent of the skilled nursing facility rate covers a wide array of personal needs. We don't manipulate so-called core services, but following assessment, we develop a plan based on what one needs, not on what a Federal or State program permits.

A second Wisconsin program deserves comment. In Sun Prarie, a small community in a rural setting, a true community serving elders has evolved which provides a wonderful example of what should develop across the Nation. A senior center offers opportunities for elders to be involved in life-enhancing programs, nutritious meals, health education, humanities and arts programs, and much more.

To those who have grown frail, the same center provides services including: adult day care; transportation; counseling; home-delivered meals; therapies; exercise programs; support groups; and various levels of housing to meet the diverse, and changing needs for shelter with services. The Colonial Club, as it is called, is a place where those with need for support and their care providers are part of a community, sharing as they are able, and receiving as they have needs.

Community-based service systems can deliver humane, effective, appropriate, comprehensive services when a solid funding foundation is provided. The NCOA has thousands of members delivering essential components of community-based long-term care on a shoestring, relying on charitable giving, volunteers, and ridiculously stingy Government funds.

With support that flows to individuals in need, rather than categorical programs, the service infrastructure will develop at the community level. Caring professionals will be attracted to provide services. The goal of meeting the needs of people where they live, and without demeaning, means-tests, and complicated administrative rules, will be achieved.

A second major concern pertains to the integration of shelter with service. Aging in place is so important to many people at risk that a national health care policy must facilitate services that make the difference between one being forced to move and one being able to continue to live in familiar settings.

What is required includes training housing managers to create supportive environments. We need to integrate services with housing to assist vulnerable residents to stay where they prefer. We need a Federal housing commitment to strengthen an effective shelter with services strategy, such as the Congregate Housing

Services Program. Housing is an essential part of a health care system.

The third issue involves the impending crisis of recruiting, training, placing, and supporting a sufficient number of formal and informal care providers. Health professionals need gerontological training. Family, care providers, neighbors, volunteers need support and respite.

We need a national service core raising service to those in great need to high priority and respect. We need to attract individuals to the caring professions, compensate them appropriately, recognize their value, and undergird them with research, training, and support. In short, the Nation's families and those unfortunate individuals suffering from chronic or acute illness need comprehensive health care financed through social insurance.

We believe that removing the cap on earnings, taxing the more than $900 billion of unearned personal income, and imposing additional taxes on alcohol and tobacco will provide a solid, fair, financial base. We can shift from buying national security through military arms to insuring national security to the defenseless, with caring arms.

Americans finds the current system confusing, biased toward acute illness and institutionalization, and terribly expensive. The committee should not tinker with an already discombobulated nonsystem, but offer the Congress a sensible, responsive, fairly financed, quality health care system that incorporates responsive, long-term care.

The health care system we envision includes disease prevention and health promotion, supports informal caregivers, and incorporates significant research and training commitments. Eligibility for services must be based on impairments and not on arbitrary demarcations of age or income. Financing should be assured by universal social insurance. Fiddling with private, long-term insurance schemes would waste precious time and limited resources.

We urge the Commission to dream no little dreams when it concerns the urgent and growing need for an adequate response to our overwhelming need for comprehensive, quality, affordable, person-centered health care.

Your leadership, Senator, will make all the difference. [Applause.]

[The prepared statement of Mr. Sykes follows:]

Testimony of James T. Sykes,
for the National Council on the Aging,
before the Bi-Partisan Commission on
Comprehensive Health Care Concerning
Long Term Care: Options and Financing.
December 13, 1989

Mr. Chairman, members of the Pepper Commission, I am James Sykes, Chair of the National Council on the Aging's Public Policy Committee. I'm also the founder of a successful community based long term care system in Wisconsin. I teach in the Medical School at the University of Wisconsin-Madison. I mention these three roles because in each I have witnessed the need for a national policy on long-term care which ensures that all persons of every age facing chronic illness have access to comprehensive, affordable, quality care.

The time is now for a truly comprehensive national policy on health care for all citizens. Stop-gap measures, tinkering with Medicare or Medicaid to add limited services for those who need care--in their homes or in institutions--with minimal funds, simply will not do. The mandate of this Commission demands a dramatically new approach to health care in America, for those who suffer the consequences of double jeopardy, serious illness and the fear of impoverishment due to the cost of care.

These consequences affect the families of those in need as surely as they do the individual. Indeed, the entire community pays the price of a system that works for some, but not others, covers certain illnesses, but not others, and provides options for some, but institutionalization and impoverishment to others.

The NCOA concurs with the direction of the findings of the Joint Economic Committee's Subcommittee on Education and Health that "National health insurance, modeled after the Canadian approach, would ensure all Americans access to high quality, affordable health care," that "standards of care based on outcomes research must be developed and applied by the health care community to limit unnecessary tests and procedures," and that research priorities must be changed. Health promotion and disease prevention and problems afflicting the elderly, such as arthritis, dementia and incontinence, must receive greater attention."

We find the words of Wisconsin's Bureau on Aging Director, Donna McDowell, precisely on target. She wrote that our long term care efforts carry the "scent of failure."

- Failure of a caregiver to be durable over the long haul.
- Failure of a long term care system to provide acceptable, affordable care.
- Failure of a government to finance the care of its chronically disabled citizens.
- Failure of a mental health system to respond to chronic mental illness.

•Failure of an economy to sustain adequate employment and retirement income.

•Failure of a marriage, of a parent.

•Failure of a social worker to "fix" a bad scene.

The failures, Mr. Chairman, are ours. Benign neglect, on the one hand, and over-reliance on a patchwork system of private/out-of-pocket spending and Medicaid, on the other, must be replaced by a comprehensive national health care system.

We have the capacity to correct these failures. Repeatedly, polls have shown that we want a sensible, affordable, quality health care system; and, those same polls show, we're willing to pay for it through our taxes rather than facing directly the high costs of long-term care. We need political leaders--with the vision and commitment of Claude Pepper--to put us on a course toward a national health system, based on a flexible social insurance model. Only such a system can provide the framework for efficiency and universality.

We need to expedite the national dialogue on such a system now or the catastrophic "Medicare crisis" and the scandal of millions of citizens lacking health care protection will become mere symptoms of a more profound economic and political crisis in the decade ahead.

I've read the testimony which the Commission has received. While the NCOA supports many of the recommendations contained in the testimony--and could provide hundreds of examples of what neglect and reliance on a means-tested patchwork non-system costs our elders, their families, and others in need of health care--I will use my limited time to draw your attention to three problems calling out for solution.

•The need to build the service infrastructure in neighborhoods and communities to provide options and support to vulnerable individuals and their families.

•The need to enable elders to continue to live where they prefer, in special places--elderly housing, group homes, continuing care retirement communities, and naturally-occurring retirement communities.

•The need to recruit and train professionals, managers, chronic care workers and volunteers to provide the care and support essential to a health care system that works for all.

Only within the framework of a comprehensive, universal national health care system can these--and countless other problems--be properly addressed.

Such a system will make long-term care an integral part of a comprehensive national health care entitlement--a goal the NCOA has advocated over many years. We recognize that an individual's physical and mental health demand appropriate attention, and that chronic care as well as acute care must be provided to all in need--not just those in nursing homes or hospitals.

In fact, we believe that for most persons care should be delivered to where one lives not the other way around with the ill transferred to facilitate providers or to simplify administrative process. We know that attention must be given to both the one directly in need of intervention and support and the providers of care. The NCOA affirms that the individual must be at the center of every care plan, controlling and sharing responsibility for his or her care.

Such a national policy must be grounded on principles such as the following, developed and approved by the Board of the NCOA with counsel from our membership units comprised of professionals and agencies working in the community with and in behalf of the elders of our society. These principles provide the foundation for an effective long-term care system.

A Yardstick for Action on Long-Term Care

1. **Shared Responsibility** Access to appropriate and affordable long-term care is a right of all Americans. While assuring such access to quality and comprehensive long-term care services is a responsibility shared by the whole society, clear roles must be accepted by government.

The federal government has a fundamental role in guaranteeing access, setting basic quality standards and, in large measure, financing that care. State governments, under federal guidelines, have responsibility to share in costs and for operational aspects of the system, including selection of providers, assurance of needed transportation services, and monitoring quality and compliance. Responsibility to assess eligibility and needs under consistent state-wide standards and to monitor the provision of services must reside with local public or private entities.

This system must encourage those who require care or who are at risk to engage in programs of self-care and in activities which can enhance recovery and wellness. Such a system must also ensure support for informal caregivers and account for their participation in care decisions.

2. **Eligibility** The design of eligibility and assessment standards and care plans should be free of limiting age and income factors. Such plans and standards must be keyed to functional impairments, including medical and psychological elements, and not to specific diseases in determining who is to be served.

3. **Financing** The financing of a comprehensive long-term care system should reflect social insurance principles, with the burden shared through federal payroll and income taxes, state and local resources, and modest copayments by users of services. Such financing could incorporate private long-term care insurance and copayments based on sliding fee-scale principles. The current system of public financing requiring the exhausting of life savings to qualify for services must be ended.

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4. **Supportive Environments** All persons requiring long-term care have an inherent right to care in the least restrictive health and social service setting. That environment is preferably and practically the home and the neighborhood. Where necessary, the setting may be institutional but with a home-like atmosphere, supportive of both care recipients and caregivers.

5. **Housing** A comprehensive long-term care policy must include support to provide an accommodating housing environment at affordable prices for persons experiencing diminishing capabilities and changing needs. Such a policy would undergird the desire to remain in one's own home or in independent senior housing facilities by providing the financing and development of appropriate home and community-based service arrangements.

6. **Providers of Care** The salaried providers of care must be appropriately trained and adequately compensated in salary and benefits. Informal caregivers should also be provided with training, counseling, respite, recognition, and, where appropriate, financal incentives.

7. **Personal Autonomy** Persons who require care in their own home or in community settings, or those who are residents of institutions, have a right to determine care decisions either directly or through caregivers and guardians, including the right to refuse or terminate services. The exercise of that right requires choice from among an appropriate range of health and social services.

8. **Rehabilitation** A comprehensive long-term care program should include rehabilitation services to restore and maintain optimal physical and mental functioning.

9. **Multi-generational Needs** Impairments affect persons of all ages. The personal and public burdens of care are largely cross-generational. Long-term care public policy must be designed to incorporate these multi-generational factors.

10. **Cultural Diversity** An effective long-term care system must respect cultural and group differences among beneficiaries as well as among providers of care.

11. **Research** A comprehensive long-term care system includes adequate outlays of public and private research resources into the causes and treatment of chronic impairment. The findings of past and existing research must be more efficiently incorporated into current community and institutional practice with special care to assist informal caregivers to utilize new information. Such research must include efforts to define and advance quality standards for long-term care.

Addressing the first problem, building community services to care for those able--with help--to remain in their homes and their home communities, let me mention Wisconsin's Community Options Program--a program that works.

I suggest that the Commission investigate the success of Wisconsin's Community Options Program. Such a study will offer evidence that providing appropriate services to individuals in their homes, and support to their care providers, is not only effective and humane, but also less costly than institutional care for the overwhelming majority of persons served. One major problem, the need for community-based service providers and care managers, is being solved in many Wisconsin communities as a revenue stream is assured through the Community Options Program. Funding follows the individual and is adequate to provide essential services.

We've found in Wisconsin that a sum equal to about 60% of the skilled-nursing facility rate is sufficient to cover a wide array of personal needs. We don't manipulate so-called core services, but, following assessment, we develop a plan that includes what one needs, not what a federal or state program permits. Our legislators and Governor, having reviewed the success of this program, are increasing appropriations for the program--evidence of strong community support.

A second Wisconsin program deserves comment. In Sun Prairie, a small community in a rural setting not far from the capitol in Madison, a true community serving elders has evolved which provides a wonderful example of what should develop across the nation. At the heart of the campus is a senior center which offers opportunities for elders to be involved in life enhancing programs, nutritious meals, health education, humanities and arts programs, and much more planned by the seniors and attractive to people who are vigorous, competent and well.

To those who have grown frail, the center provides services including adult day care, transportation, counseling, home delivered meals, therapies, exercise programs, support groups and various levels of housing to meet their diverse and changing needs for shelter with services.

Financed largely by the participants with support from local businesses, the United Way, and a mix of modest federal, state, local and county funds, the Colonial Club--as it's called--has become a "community" in which those with need for support and intervention, and their care providers, are part of the community, sharing as they are able and receiving as they have needs. A home health care agency--so badly needed by this quadrant of Dane County--has gone out of business because the federal government reneged on its commitment to reimburse such agencies in a timely and adequate manner.

The examples I've cited--Wisconsin's Community Options Program and the Sun Prairie Senior Center--underline NCOA's evidence that community-based service systems can deliver humane, effective, appropriate, comprehensive services when a solid funding foundation is provided. The NCOA has thousands

of members currently delivering essential components of community long-term care on a shoestring--relying on charitable giving, volunteers, and ridiculously stingy government funds.

We can and must do a whole lot more to build supportive environments around where one lives--in the community.

With support--that flows to individuals in need rather than to categorical programs--the service infrastructure will develop at the community level, caring professionals will be attracted to provide services, and the goal of meeting the needs of people where they live, and without demeaning means tests and complicated administrative rules, will be achieved.

A second major concern the NCOA would like the Commission to consider pertains to the integration of shelter with services. The idea of "aging in place" is so important to so many people at-risk that a national health care policy must facilitate services that make the difference between one being forced to move and one being able to continue to live, independently with help, in familiar settings.

What is required includes training housing managers to create supportive environments for those residents increasingly in need of assistance. We need a system that will provide services to people no matter where they live. We don't need more evidence to prove that limiting services to people already in institutions--or imminently at risk of institutionalization, or recently released from institutions--makes no sense.

We need the strong support of both health care providers and housing industries to ensure that we have affordable, appropriate housing designed to enable individuals at-risk to age in place. We need to find ways to integrate services with housing to assist vulnerable residents to stay where they prefer--in their homes and apartments and not forced to relocate to nursing homes or to inappropriate shelter.

The supply of appropriate, affordable housing has shrunk over the past decade due to mis-guided efforts to limit the nation's debt at the expense of maintaining and enlarging the supply of decent housing. We know what needs to be done. We need a federal housing commitment to strengthen an effective shelter with services strategy such as the congregate housing services program. Housing is an essential part of a health care system.

Mr. Chairman, the NCOA's third issue involves the impending crisis of recruiting, training, placing and supporting care providers--including both highly-trained health and social service professionals and chronic care workers who provide so much of the care vulnerable citizens require. In addition, we need to ensure that family care providers, neighbors, volunteers--those who now and in the future will continue to provide the bulk of care at home and in the community--receive support and respite.

An effective national health care system must guarantee that the human resource needs of increasing numbers of chronically ill individuals and their families will be met. We need a national service corps, raising service to those in greatest need to high priority and respect. We need to incorporate strategies to attract individuals to the caring professions, compensate them appropriately, recognize their value to a caring nation, and undergird them with research, training and support. This matter--of who will care for those in great need--demands thoughtful planning and substantial resources.

Mr. Chairman, the NCOA has reviewed national survey data and confirms the findings with the comments of our members throughout this nation--that the nation's families and those unfortunate individuals suffering from chronic or acute illness--need comprehensive health care, financed through social insurance.

We believe that removing the cap on earnings, taxing the more than $900 billion of unearned personal income, and imposing additional taxes on alcohol and tobacco will place a solid, fair, financial base under a national health care system.

We must shift from buying "national security" with military arms to ensuring personal security to the defenseless of this nation with caring arms.

Americans find the current system confusing, biased toward acute illness and institutionalization, and terribly expensive. The Commission should avoid tinkering with an already discombobulated non-system and offer the Congress a sensible, responsive, fairly financed, quality health care system. NCOA members, with forty years of experience in providing care and services in the nation's communities, will assist the Commission in designing such a system and building a constituency for its enactment.

The National Council on the Aging strongly supports a national health care system that incorporates a responsive long-term care system. The health care system we envision includes disease prevention and health promotion, supports informal caregivers, and incorporates significant research and training commitments. We believe that eligibility for services must be based on impairments and not on arbitrary demarcations of age or income. Financing this program requires universal social insurance; fiddling with private long term care insurance schemes would waste precious time and limited resources.

We urge the Commission to "dream no little dreams" when it concerns the urgent and growing need for an adequate response to our overwhelming need for comprehensive, quality, affordable, person-centered, health care. Your leadership, Senator Rockefeller, is the key to reaching the goals we share.

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Chairman ROCKEFELLER. Thank you, Jim, very much. Let me just ask each of you one question. We will probably have others that we will submit in writing for you.

Jim, in your yardstick for action on long-term care, you said that financing could include private, long-term care insurance. Then, later on, you said, as you just did that fiddling with private long-term care insurance schemes would waste precious time and limited resources. Now those are two different statements. We are looking—in the Pepper Commission—at the idea of reforming our private insurance system in this country, which is regulated by the States. States don't usually have very large agencies to do this job.

I have had, interestingly enough, some people from the insurance industry, including the head of a very major insurance company, come to me and say: "Look, you and the Pepper Commission ought to tell us what we know we ought to do, because if you do, we will do it." That is interesting to me.

What you are saying on the one hand, is "Keep private insurance out," and on the other hand, you are saying, "Maybe we could do something with private insurance."

I am kind of interested in where you stand on that.

Mr. SYKES. We need to put it in sequence. The yardstick, which is in the text, was about 9 months ago when the National Council on the Aging; the Pepper Commission; and the Robert Wood Johnson grants to Wisconsin, among others—for which I have had some responsibility—asked in a very open way: "Is there a role, and if there is, what is the role for private insurance in long-term care?"

You have heard too much—because I have read you're testimony. We have learned too much out there in the States and listening to testimony, and the results of Medigap insurance failures to continue to come along with that salute to the private sector and private long-term care insurance as though that is an answer. I wish I could tell you—based on the research that I've done, and the reports that I have read, and the testimony that you have received—that there is in fact a place for private long-term care insurance. I don't see it. The conditions for such a program, unless it were truly universal and national, will simply work against the very goals you have described on the Pepper Commission and what the witnesses have said today. We are changing our position largely because of what you have heard and what we have learned.

Chairman ROCKEFELLER. I thank you very much.

Dr. Freeman, you talked about some of the bureaucratic and psychological barriers that people have when they are trying to get help and they are poor. Medicaid is criticized a lot. It is for the poor. Physicians criticize it because it doesn't reimburse very well—which indeed it does not. It is a program, as you know, that both the State and the Federal government pay for.

What if there were some kind of a system wherein the poor and the nonpoor were treated alike? Would that help? In other words, if you took away the stigma, so to speak, of Medicaid?

Dr. FREEMAN. I believe it is a matter of human dignity that everyone wants to be treated fairly and justly, particularly with regard to access to medical care. Now the Medicaid system you have described very well. It is a system that allows for people to get in for treatment of disease at the point of symptom. It is not a

system that stimulates preventive type of care. In fact, it doesn't even pay for it in most parts of the country. You cannot get a pap smear for prevention under Medicaid, for example.

This won't solve the problem of cancer. By the time people come in for real episodes of pain or bleeding or any other complaints, cancers are usually very late. So I think not only do we need to extend coverage to the people who are uncovered, as you point out, but we need to make the Medicaid system a friendlier system to serving people in the way they need to be served.

Chairman ROCKEFELLER. Which in turn has something to do with the availability of people and personnel who are trained. You know, it is interesting, the health care system is the largest employer of people in this country. It is the No. 1 employer. It has always been interesting to me—I can remember 10 years ago, you couldn't get men to go into elementary school teaching. That always struck me as crazy, because kids at that age need role models who are women, and they need role models who are men. Now men are going into elementary education. It was kind of a stigma evidently, 10, 12, 15 years ago, which was ridiculous at that time.

Sometimes I have that feeling, for example, about nursing. I have never understood why it is that men shun this profession—nursing is just an unbelievable way to help people. Of course, it is a very stressful job, a very hard job, but talk about really helping people—whether it is at home, or in the hospital, or through community-based care—it is a remarkable service. Yet it is still reasonably unusual for men to go into nursing, even though there are a lot of people in this State and others that are unemployed. Young men could get trained as nurses, and would start off with salaries, perhaps, at $22,000, $23,000, $24,000 a year, and do something which is really meaningful in life.

I think you are talking, both of you, about the need for—you used the word infrastructure, or whatever—good people to serve as health care providers. We have got to get people to understand that health care is one of the greatest services that they can do, and they do get paid for it. The health care industry is a well-paying industry, for the most part——

Mr. SYKES. For the professionals, unfortunately, not for the chronic care workers. We've got to do something about them as well.

Chairman ROCKEFELLER. I understand that. There you get into the problem of State employees and everything else. I appreciate both of you very, very much. We have fallen a little bit behind time in our scheduling here. I want to take a 5-minute break and then we are going to come back with the West Virginia perspective on access to health care and long-term care.

Thank you all.

[Whereupon, a recess was taken.]

Chairman ROCKEFELLER. Ladies and gentlemen, if we could come back in and settle down. The clock is running.

CAMC [Charleston Area Medical Center] has asked me to make the following announcement: If you are parked in C lot or in lot C, I guess, put "PC," those two initials, on your card and you will be able to get out of the lot without paying. There is a table just in

front of the doors up there to answer questions or to mark cards for those who do not have pencils and pens.

Incidentally, I failed to mention at the beginning my thanks to CAMC and their tremendous cooperation on this hearing.

It is awfully important to have this public hearing. Every word that is spoken here becomes a part of the national record of the Pepper Commission. This is not just a conversation between four people over there and somebody here. This is all part of the national record and it is all part of what we refer to and learn from as we develop our policies.

Our next panel looks at all of this from the West Virginia perspective.

Taunja Willis-Miller, who is secretary of the West Virginia Department of Health and Human Resources, a lady I greatly respect.

David Brown, whom I used to know before he had a single gray hair, now the West Virginia Commission on Aging director. Dave, when I heard that, I just jumped up and down for happiness, because we used to work together and we still do and we always will.

Phil Goodwin, who is president of the Charleston Area Medical Center, who in my thinking has written very bold and interesting things about health care in West Virginia, taking very strong stands, and I think has major contributions to make to all of this.

Dr. Derrick Latos, who is president of the West Virginia Medical Society and is one of the people with whom I conferred when we were developing a new approach called Medicare Physician Payment Reform. This approach is passed now into law, signed by the President. It will bring more primary care physicians into the State of West Virginia and all across the country, for reasons that I will not get into now, but Rick Latos is an excellent leader of the West Virginia Medical Society.

Taunja, why don't we just start with you.

STATEMENT OF TAUNJA WILLIS-MILLER, SECRETARY, WEST VIRGINIA DEPARTMENT OF HEALTH AND HUMAN RESOURCES

Ms. WILLIS-MILLER. Thank you, Senator Rockefeller. It is a pleasure to be here today and I am thrilled that the Pepper Commission is having this hearing in Charleston.

There are three significant areas to discuss in connection with access to care. First, West Virginia, as does the rest of the Nation, has a great number of citizens, about 300,000, without any form of health care insurance. These people in many instances have significant problems with access to care.

Last week I had the opportunity to see a video of the speech that Senator John Kitzhaber made to the Kentucky Medical Association. As I am sure you know, Dr. Kitzhaber is the physician who is also a leader in the Oregon State Legislature.

While most of the speech dealt with the Oregon system of funding health care, another very interesting part was his historical review of access to care issues. He talked about the traditional method of funding indigent care by shifting the cost to private and Government third-party payers, but that traditional method has broken down.

First, the third-party payers have established cost-containment measures, thus shrinking the pool from which indigent care can be funded. The cost, then, has shifted somewhat from the third-party payers to the medical community itself. With malpractice and other concerns, the medical community is either unable or unwilling to assume the cost.

Second, care for the poor is no longer limited to our most needy citizens. As medical insurance has become more expensive and as our economy has shifted from industrial to service industries, more people in the work force are uninsured, and in addition, as State funds have become tighter, States have tightened eligibility for Medicaid.

One of the things that we have been looking at in the division of human services, which is experiencing financial difficulties, is tightening the Medicaid eligibility. We have rejected that idea because all that does is put 52,000 people in addition to the 300,000 that are already uninsured. So that is something that we are trying very hard not to do in the State of West Virginia.

The Children's Defense Fund began a recent publication on maternal and child health with a vignette of a child who died. She died because her mother was not neglectful but delayed taking her to the doctor for a fever because her mother did not know how she would pay. I hope that is not occurring in West Virginia. I do not have any specific examples of that occurring but I fear that it may.

In 1986, 1 out of 6 West Virginians was without health care coverage, and it is particularly a problem because West Virginians are among the most unhealthy people in the country.

In addition to the uninsured, West Virginia has experienced difficulties in access to care for our Medicaid population. Some health care providers just do not "take the card" and even if they do, referrals can be a problem. To be fair, Medicaid has been slow in paying in recent years but with the help of the 1989 legislature and a significant supplemental appropriation, we are much more current in paying our bills.

There are still problems. While our payments are adequate, others need review. West Virginia has to switch its emphasis and to switch its emphasis, it has to switch its payment system to emphasize primary care, and even before primary care, preventive care, and it has to switch its emphasis from institutional to inhome long-term care.

The Physician Payment Reforms that you supported are a great step in the right direction and we need to be doing that on a State level also. But part of the problem is that in tight financial times, it is hard to make those changes. It is hard to shift your money because you have acute care needs that you are funding and it is hard to free up the money from that to put it where it should be.

We have been taking some steps to address access to care problems for Medicaid beneficiaries with the Omnibus Health Care Act. We have said that if a physician or other health care provider treats workers' comp or PEIA [Public Employees Insurance Agency] beneficiaries, both systems which pay much better than Medicaid, you also have to treat the State's Medicaid patients because they are State citizens the same as the PEIA and the workers' comp beneficiaries are.

Then even people who have insurance in West Virginia have problems with access to care, particularly access to care in their local communities. For one thing, access is simply more difficult in rural communities and over 60 percent of West Virginians, as you well know, live in rural areas or in communities with less than 2,500 people.

Lack of transportation compounds the problem, particularly for the elderly. The terrain, the weather, and even though the division of highways is making rapid improvements, to some extent, the road conditions, isolated households, all of this severely limits access, particularly for the elderly.

We are spending a lot of money on health care but even at that, access is inadequate. Of our 55 counties, 36 are designated as medically underserved by the Federal Government, and parts of 12 other counties are so designated. There were 35 small and rural hospitals serving the State in 1987 but 5 of these have since closed, leaving at least two of our communities with no alternate acute care, and there are others that are in significant financial difficulty.

Rural hospitals are essential to accessible health care in rural West Virginia and they also, as you mentioned with respect to health care being a substantial employer, impact more than just the health care of the people who live in those towns.

Now, that is not to say that the hospital facilities in West Virginia should remain at status quo. They may need to be changing their mission and their focus and we need to develop linkages.

Health personnel is also a problem. Recruitment and retention, as the gentleman from the Cancer Society mentioned, is a problem, particularly in rural areas. We hear a lot of reasons that cause problems in retention and recruitment, such as lack of familiarity or exposure to the rural areas and lack of contact in nurturing while they are there and overwork for underpayment.

The State has benefited from the National Health Service Corps, and it is estimated that as many as 40 primary care physicians may leave the State as a result of Federal cutbacks in the National Health Service Corps. Combined with the aging of the primary care physicians in rural areas and the changes in the licensing of foreign doctors.

Chairman ROCKEFELLER. The Service Corps will be leaving?

Ms. WILLIS-MILLER. When their time expires, and the concern is that they will not be replaced.

Chairman ROCKEFELLER. I think that is a legitimate concern. My understanding today is that there are only about four service corp doctors per year coming into West Virginia, whereas there used to be about 40 per year.

Ms. WILLIS-MILLER. This is a statistic that I took from some information that was compiled in connection with the SB-420 study which is going on that Dr. Bob Walker, who I think has spoken about here today. So perhaps I have taken it somewhat out of context. We will have to check with Dr. Walker and make sure and I will get back with you on that.

Chairman ROCKEFELLER. Thank you, Taunja.

Ms. WILLIS-MILLER. At any rate, we are not using nurse practitioners and other physician extenders quite as effectively as we should and we need to work on that.

There are also some problems with emergency medical care because 80 percent of our medical personnel, emergency medical personnel, are volunteers. They do a wonderful job, but a volunteer system is difficult for funding and training.

We also have a particular problem with prenatal and obstetrical care. The number of providers has decreased by 44 percent in the past 2 years. This is a particular problem because we have the second highest percentage of births to white teenage mothers, the first in the Nation in percentage of low birth-weight infants born to teenage mothers and the third highest in the Nation in numbers of mothers receiving inadequate prenatal care.

I mentioned the Senate bill 420 study. It is something that the legislature required to explore, among other things, the role of medical schools and health care delivery. The initial study was delivered December 1 and from that, we have established a committee in which many of the people who you have seen today are going to be on that committee, I think, and we are looking forward to its being very productive.

Access to care is a significant problem. Gov. Caperton spoke at the WVU [West Virginia University] conference on health care education in the 21st century and he gave a quote from Thomas Huxley, that Thomas Huxley visited Johns Hopkins and he was asked what he thought of America's size and he said: "I can't say that I am impressed by either your size or your material resources. The great issue, it seems to me, is what you are going to do with these things."

I am convinced that with your continued strong efforts and with our efforts here in West Virginia, working cooperatively, we are going to be able to use those resources to the best advantage of all our citizens.

I appreciate this opportunity to share our concern.

[The prepared statement of Ms. Willis-Miller follows:]

DRAFT REMARKS TO THE PEPPER COMMISSION, DECEMBER 13, 1989, REGARDING ACCESS TO CARE - TAUNJA WILLIS MILLER, ON BEHALF OF THE WEST VIRGINIA DEPARTMENT OF HEALTH AND HUMAN RESOURCES

There are three significant areas to discuss in connection with access to care. First, West Virginia, as does the rest of the nation, has a great number of citizens - 300,000 - without any form of health care insurance. These people in many instances have no access to health care.

I just last week had the opportunity to see a video of the speech Senator John Kitzhaber, M.D. gave to the Kentucky Medical Association. Dr. Kitzhaber is the physician who is also a leader in the Oregon State Legislature. While the most noteworthy part of the very good speech was a description of the Oregon system of funding health care, his historical review of access to care issues was also very interesting. He talked of the traditional method of funding indigent care by shifting the cost to private and governmental third-party payors. That traditional method has broken down for several reasons. First, the third-party payors have established cost-containment measures, thus shrinking the pool from which indigent care can be funded. The cost, then, has shifted somewhat from the third-party payors to the medical community itself. With malpractice and other concerns, the medical community is unable and/or unwilling to assume such cost. Second, "indigent care" is no longer limited to our most needy

citizens. As medical insurance has become more expensive and as our economy has shifted to service industries, more people in the work force are uninsured. In addition, as state funds have become tight, states have tightened eligibility for Medicaid.

The Children's Defense Fund begins its recent publication on maternal and child health with a poignant vignette of a child who died. Her mother, not through neglect but through the fear of not being able to pay, postponed taking the child to see a doctor until it was too late. I would like to think this could not happen in West Virginia, but it I fear it could.

In 1986, one out of six West Virginians was without health care coverage. Lack of access to care is particularly a problem in West Virginia because West Virginians get sick more frequently and die earlier in greater numbers than other Americans. For example, studies done by the State Division of Health over the past several years show that premature deaths from heart disease in West Virginia have been as high as 30% above the national average, and our white infant mortality rate is 12% higher than the national average.

In addition to the uninsured, West Virginia has experienced difficulties in access for Medicaid beneficiaries. Some health care providers do not "take the card." Even if a Medicaid beneficiary has a primary care provider, referrals can be problematic. To be fair, West Virginia's Medicaid system has been

very slow in paying in past years. A generous supplement from the 1989 State Legislature and adequate funding for FY 1990 have helped us make great strides, but there are still problems.

While many of our Medicaid payments are adequate, others need reviewed. West Virginia must switch its emphasis and, thus, its payment incentives from acute care to, first, preventive care and, then, primary care and from institutional to in-home long-term care. The increased payment for primary care providers under Medicare is a step in the right direction, and we applaud Senator Rockefeller for his support of that. The State now needs to address the problem for Medicaid. In tight financial times, however, it is difficult to find money to encourage preventive and primary care while still funding acute care.

West Virginia has recently taken steps to address access to care problems for Medicaid beneficiaries. The Legislature in 1989 enacted the Omnibus Health Care Act. West Virginia has historically paid well for PEIA and Workers' Compensation beneficiaries. The Act, which carried its share of controversy, requires that if a provider serves PEIA and Workers' Compensation patients he must also serve Medicaid patients. We do not yet know what impact the Act will have.

Third, even those West Virginians who can pay for medical care, whether personally or through a third-party payor, experience problems with access to care, particularly in their local community. For one thing, access is more difficult in rural areas,

and over 60% of West Virginians live in rural areas or communities of less than 2500 residents. Lack of transportation compounds the problem, particularly for the elderly. Terrain, weather, road conditions (although the Division of Highways is making rapid improvements), isolated households all may severely limit access of care to the elderly. Many elderly do not drive, and must pay others to take them to medical care. Access to rural clinics and offices often does not include handicapped facilities.

In large part because of significant uncompensated care, the proportion of hospital expenses to personal income was greater for West Virginians than for the citizens of any other state in 1987. Although, according to American Hospital Association reports, West Virginia's 1987 hospital admissions per 1000 actually decreased at a rate greater than the national average. West Virginia's rate of hospital admissions is among the highest in the nation. Even with these statistics, access to health services for our more rural citizens is inadequate. Thirty-six of our 55 counties are designated entirely as medically underserved areas by the federal government, and parts of twelve other counties are so designated. Although there were 35 small and rural hospitals serving the State as late as 1987, five of these have since closed, leaving at least two of their communities with no alternative acute care hospital. Of those remaining, another five are in significant financial difficulty and are at risk of closing. It should be especially noted in West Virginia how essential rural hospitals are in the

delivery of accessible health care to those individuals living outside major urban areas. Their loss may have far wider effects than just the loss of substantial health services. Such a loss can result in the loss of physician services, as well as population, jobs, revenues, and overall community income.

This is not, however, to say that hospital facilities in West Virginia should remain at the status quo. We must determine what services should be available in a community, how far it is reasonable to travel to receive other services and how we link the two together. Some rural hospitals may have to change their goals and mission. But they must continue to play an integral part of the health care delivery system in West Virginia.

As I am sure you know, one of the biggest problems faced by rural hospitals is the preference toward large, urban hospitals given by Medicare funding.

The linkages mentioned above are essential if we are to provide health care in rural areas. A primary care center or a local hospital, which serves the essential health needs of the community and receives community support, can thrive if it is adequately linked to the secondary and tertiary providers needed. But facilities without staff are useless.

Although the number of health personnel has been increasing in West Virginia, maldistribution of manpower continues to be a problem particularly for rural areas. The availability and accessibility of primary medical care, the point of entry into the

health care system, are dependent upon the location of health personnel and facilities in adequate numbers to meet the needs of the population. The topography and geographic isolation of many West Virginia communities increase the difficulty of recruiting and retaining quality health professionals. The State has benefited from the National Health Service Corps, and it is estimated that as many as 40 primary care physicians may leave the state as a result of federal cutbacks in the National Health Service Corps. Combined with the aging of the primary care physicians in rural areas and changes in the licensing of foreign-trained physicians, the shortages will become worse. To compound this problem, other types of health providers - physician extenders - are not being used to best advantage. Nurse practitioners, nurse clinicians, nurse midwives and physician assistants are cost-effective providers who deliver high-quality health care when properly supported and supervised.

Recruitment, distribution, and retention of qualified health care personnel is a problem particularly for rural areas of the state. Some of the concerns most often mentioned by doctors in failing to select or stay in rural areas are lack of familiarity or exposure, lack of contact and nurturing, and overwork for underpayment.

There is an increasing need for registered nurses, particularly for nursing homes, hospitals and community health settings. Many rural counties have special needs for

psychiatrists particularly for the youth and aged. The problem may be addressed by increased training for primary care providers

Eighty percent of the emergency medical technicians in West Virginia are volunteers. The emergency vehicles used by many volunteer services are in great need of repair of replacement. Many communities have no evening, weekend or holiday medical services.

West Virginia has a particular access problem with respect to prenatal and obstetrical care. The number of providers has deceased by 44% in the past 2 years. This is a particular problem because West Virginia is second highest among the 50 states in percentage of births to white teenage mothers, first in the nation in percentage of low birth-weight infants born to teenage mothers and third highest in the nation in number of mothers receiving inadequate care.

One additional step recently taken by West Virginia was enactment of S. B. 420. S.B. 420 required that a study be delivered to the Legislature by December 1, 1989, regarding the medical schools in health care delivery and their role in health care delivery. That study, done by Dr. Bob Walker, will serve as the starting point for involving the medical schools as a solution to health care - particularly access - problems.

Access to care is a significant problem in West Virginia. We appreciate this opportunity to share with the Commission our concerns about this problem. I particularly liked a portion of Governor Caperton's speech at the WVU Medical School Conference on Medical Education in the 21st Century:

"Undeniably....the situation is sobering....and as I was reviewing the numbers....and thinking about the purpose of our coming together today....I recalled an incident that occurred at Johns Hopkins University.

Once during a visit to the University....the English biologist Thomas Huxley was asked by a student....what he thought of America's size....

And Huxley said....'I can't say that I'm impressed by either your size or your material resources.

The great issue....it seems to me....is what you're going to do with all these things.'

That is also the great issue facing our health care system....in America....and in West Virginia....

and it is the issue we focus on here today.

What will we do with our resources?"

With your efforts and ours, we know improvements will be forthcoming.

Chairman ROCKEFELLER. Thank you, Taunja. Dave Brown.

STATEMENT OF DR. DAVID K. BROWN, EXECUTIVE DIRECTOR, WEST VIRGINIA COMMISSION ON AGING

Dr. BROWN. Thank you so much. It is a pleasure, Senator Rockefeller, and an honor to be here today and speak to you and the Pepper Commission and to represent the West Virginia Commission on Aging.

As we fully realize, long-term care issues are immediately tied to demographic, life conditions and socioeconomic factors among senior citizens. If adequate health care at reasonable costs were available to all age groups in need, we would probably not be meeting here today.

Some 350,000 citizens living in West Virginia today are over 60 years of age. They comprise 18 percent of the State population, or 1 in every 5. By the year 2000, West Virginia's 84-plus population is expected to increase 2½ times to 48,000. All statistics we have at our command today project this population group as the heaviest users of long-term care.

As is true nationally, older West Virginia females outnumber males, comprising 59 percent of the 60-plus population. Some 105,000 elders in the State live alone, and you know the jeopardy of living alone among the elderly population; 186,000 have less than a high school education and some 206,000 have a total annual household income of less than $12,000 a year.

From a recent needs assessment completed by the Commission on Aging, some 60,000 senior citizens consider themselves to be homebound because of illness, disability, or lack of access to services. Over 164,000 report their health status to be fair to poor.

It is axiomatic that health care and physical well-being are linked to levels of economic development. Therefore, long-term care can and should be examined from the context of that perspective. Strategies for reducing dependency and long-range planning for human services go hand in hand with long-range economic development strategies.

Social gerontologists project an ever-increasing demand for physician visits, short-stay hospitalization, incidents of physical limitations due to chronic conditions, and an increase in nursing home care. The greatest demand, however, is projected to be for home health and community-based social services.

The National Association of State Units on Aging [NASUA] and area agencies on aging have likewise documented this spiraling demand. Hand in hand with these projections are findings submitted by the House Select Committee on Aging, which indicate per capita cost by elderly for health care will have tripled since 1971, reaching an estimated $2,409 annually this year.

The Health Care Finance Administration documents every year the Medicaid and Medicare expenditures targeted to the hospitals, nursing homes and physician visits. Ample voices have been raised to decry the inadequacy of present models of service delivery, yet we face a virtual deluge of demand in the immediate decades ahead.

General consensus exists that any sound system of long-term care include a focus of community-based inhome services to carefully target most frail and vulnerable elderly. In addition, case management is widely accepted as the lead gatekeeping administrative service.

Maintaining self-sufficiency and independence among clients and avoiding or delaying unnecessary institutionalization are prime goals. Long-term care, likewise, emphasizes the role of family and other community-based informal caregivers.

Though the technology in carefully targeting services to those most in need is relatively new, the focus of such instruments is properly placed on accurate measures of activities of daily living capacity. Such tools need to be mandated for careful utilization review, which is a reasonable first step in cost containment.

Long-term care systems need accurately to screen potential users so that only the most needy are served. The Older Americans Act can well serve as a national standard with targeting criteria based on social and economic need, low-income minority and frail, vulnerable status.

Congress, however, needs to rethink, in the next reauthorization cycle, modifications to the national funding formula which is based entirely on population.

Senator, I have had the privilege to work with your good friend, Senator Cochran, the last several years in trying to deal with the question of a national funding formula in the Older Americans Act. Though the targeting provisions are very bold, demanding States to prioritize services very carefully to those with the greatest socioeconomic need, to the low-income minority, to the frail and vulnerable, the national funding formula that the Administration on Aging uses to fund States considers only population as its sole criterion.

I think there is a blatant misconstruction in the act between the national funding formula for States and the targeting provisions which mandate the States to serve those most in need, and I hope that a long look can be given this inequity during the next reauthorization cycle.

A second component of a sound long-term care system is the development of long-term care insurance packages aimed toward inhome services and not merely benefits for institutional care. Younger populations need to be presented with the urgency to plan carefully for their older years through the attractiveness of such products.

West Virginia has taken some leadership with the recent passage of the Long-Term Care Insurance Act which embraces rehabilitation, maintenance, and personal care services.

Elderly people are quite willing to share the fair cost of care. Voluntary contributions in the meals and social service programs, titles III–B and III–C of the Older Americans Act, realized $1.8 million from older West Virginians last year.

Nationally, elders receiving Older Americans Act services have voluntarily contributed nearly $40 million, all of which is reinvested to expand the services which generated the contribution.

Chairman ROCKEFELLER. Dave, your 5 minutes is up, so please wind up.

Dr. BROWN. I sure will. Expanding the Medicaid Waiver Program with community-based waiver, a very real program which could bring millions of dollars into West Virginia, is one other response to long-term care and certainly an intergenerational program which is sensitive to the needs of all age groups.

We need to avoid intergenerational conflicts in West Virginia in prioritizing long-term care. That is self-defeating. The Community Care Program which the State has also passed is another step in the right direction, and we are getting about the business of reorganizing State agencies to eliminate fragmentation between health, medical, and social services. We need to integrate those more carefully for comprehensive focus.

Thank you very much.

[The prepared statement of Dr. Brown follows:]

REPORT TO THE PEPPER COMMISSION: U.S. BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE

Dr. David K. Brown, Executive Director
West Virginia Commission on Aging

Senator Rockefeller, members of the Pepper Commission, ladies and gentlemen, thank you for the honor and opportunity to extend comments on the vital and critical issue of long term health care for older West Virginians. There is no more timely nor immediate topic we could be discussing today.

As we all fully realize, long term care issues are immediately tied to demographic, life conditions and socio-economic status factors among senior citizens. If adequate health care at reasonable costs were available to all age groups in need, we would probably not be meeting here today.

Some 350,000+ citizens living in West Virginia today are over 60 years of age - they comprise 18 percent of the state population - one in every five. By the year 2000, West Virginia's 85+ population is expected to increase 2½ times to 48,000. All statistics we have at our command today project this population group as the heaviest users of long term care services and facilities.

As is true nationally, older West Virginian females outnumber males - comprising 59 percent of the 60+ population. Some 105,000 elders in the state live alone, 186,000 have less than a high school education and 206,000 have a total annual household income of less than $12,000.

Findings from a recent needs assessment completed by the West Virginia Commission on Aging indicate that 20,000 senior Mountaineers consider themselves to be homebound because of illness, disability or lack of access to services. Over 164,000

report their health status to be fair to poor. It has been amply documented that unattended health and medical problems in earlier life are greatly exacerbated with age. Over 228,000 elders claim Medicare or Medicaid insurance coverage.

It is axiomatic that health care and physical well-being is linked to levels of economic development. Therefore, long term care can and should also be examined from the context of that perspective. Strategies for reducing dependency, and long range planning for human services go hand in hand with long range economic development strategies.

National Trends

Social gerontologists project an ever-increasing demand for physician visits, short-stay hospitalization, incidents of physical limitation due to chronic conditions, and a 64 percent increase from 1980 to 2000 for nursing home care. The greatest demand, however, is projected to be for home health and community based social services. The National Association of State Units on Aging (NASUA) and Area Agencies on Aging have likewise documented this spiraling demand. Hand in hand with these projections are findings submitted by the House Select Committee on Aging which indicate per capita payments by elderly for health care have tripled since 1971 and now reach an estimated $2,409 annually. By this year, fully 20 percent of income of elderly will be spent on health and related care.

The Health Care Finance Administration has documented every year since 1984 Medicaid-Medicare expenditures targeted to hospitals, nursing homes and physician visits. Ample voices have been raised to decry the inadequacy of present models of service delivery, yet we face a virtual deluge of demand in the immediate decades ahead.

Issues for the Agenda

General consensus exists among social gerontologists, policymakers and public service agencies that any redesigned system of long term care includes a focus of community based, in-home services to carefully targeted most frail and vulnerable users. In addition, case management is widely accepted as the lead gatekeeping administrative service. Maintaining self sufficiency and independence among clients and avoiding or delaying unnecessary institutionalization is a prime goal. Long term system likewise emphasizes the role of family and other community-based informal caregivers.

Though the technology in carefully targeting services to those most in need is relatively new, the focus of such instruments is properly placed on accurate measures of activity of daily living capacity. Such tools need to be mandated for careful utilization review, which is a reasonable first step to cost containment. Long term care systems need to accurately "screen" potential users so that only the most needy clients are served. The Older Americans Act can well serve as a national

model with targeting criteria based on social and economic need, low income, minority and frail, vulnerable status. Congress, however, needs to rethink, in the next reauthorization cycle, modifications to the national funding formula to states which is based entirely on population.

A second component is the development of long term care insurance packages aimed toward in-home services and not merely benefits for institutional care. Younger populations need to be presented with the urgency to plan carefully for their older years through the attractiveness of such products. West Virginia has taken national leadership with the recent passage of the West Virginia Long Term Care Insurance Act which embraces rehabilitation, maintenance and personal care services. Group coverage is also included. Pre-existing conditions and prior institutionalization issues are likewise adequately addressed in the bill.

Elderly people are quite willing to share the fair cost of care. Voluntary contributions in the meals and social service programs, Titles III-B and C of the Older Americans Act, realized $1.8 million from older West Virginians this year. Nationally, elders receiving Older Americans Act services have voluntarily contributed nearly $40 million, all of which is reinvested to expand the service which generated the contribution.

West Virginia, along with other states, currently participates in the 2176 home and community based waiver program

under Medicaid. This program, which matches state dollars 3-1, needs to be quickly expanded statewide so that the state can claim its fair national share of waiver dollars. The aging network, with stable planning and coordination within the area agencies on aging and county-based projects and providers of long experience, is well-suited to deliver the vast potential for service of the waiver program. Locating state dollars to call down federal resources is a vexing though not insurmountable issue.

The intergenerational aspects of this program which makes services available to all qualifying age groups is particularly sound and attractive. More stress needs to be placed on intergenerational outreach and compatibility of need to avoid damaging intergenerational conflict over care priorities.

The state has also taken a bold and venturesome step forward in the development of the Community Care Program geared to community based services in the long term care context. This vital program, which could as well serve as a national model, needs to be carefully nurtured and adequately funded. A particular pioneering aspect of the program is the call for the establishment of common entry points, on the local level, where clients can more easily access the human services system in their behalf.

NASUA has recently submitted a long term care proposal based on the predicate that the fist dollars invested in long term care

should be on the community and in-home level. A new Medicare Part C is proposed with lead case management services funded by eliminating the 45,000 cap. This proposal, which meets the criteria suggested above, is worthy of the Commission's close scrutiny.

Though the Catastrophic Health Protection Act is under major revisions, the Medicaid "buy-in" features of the program need to be preserved, especially as it benefits smaller more rural states like West Virginia. Inability to pay premiums or co-pays need no longer be a barrier to access to adequate care.

Finally, the state is currently undergoing a comprehensive reorganization of major human services agencies which are now being brought together in common configurations to more closely coordinate and integrate services. The traditional dichotomy between health and social services is rightfully breaking down. Clearer allocations of roles and authorities are forthcoming and a new, all too long delayed spirit of focus and discipline is being adopted on the state, regional and local levels.

Only such a comprehensive commitment will adequately address the challenge ahead. West Virginia is on the exciting frontier of long term care issues. Decisive leadership and commitment, such as the Pepper Commission nationally provides, has been long awaited and long overdue.

As the Commission decisively frames the broad guidelines of a national long term care system, states will eagerly embrace the

commitment, and with a sense of urgency and unity, to get on with its primary responsibility of serving those truly most in need of its service capability.

Thank you.

Chairman ROCKEFELLER. Thank you, David, very much. Phil.

STATEMENT OF PHILLIP H. GOODWIN, PRESIDENT, CHARLESTON AREA MEDICAL CENTER

Mr. GOODWIN. Thank you, Senator Rockefeller, and welcome home. We are very appreciative of the opportunity to offer this statement for your deliberations.

I perceive that the West Virginia perspective is not substantially different from that of our Nation as a whole. I am sure that in your hearings and research you are compiling reams of material and data gathered relative to the issues that we have heard about today and I doubt that I have much new or dramatic that could add to the kinds of stories and information that you are hearing.

My goal, therefore, is to emphasize the growing magnitude of this impending crisis and urge thoughtful and expedient actions. We are facing a crisis in health care in our country and we cannot wait for a complete study and research to begin our responses.

Approximately 35 million of our citizens are falling between the cracks of adequate resources to obtain health care.

The problem is not the cost of health care services. The problem is not access to health care services. The problem is not who pays for health care nor is the problem simply a lifestyle and acceptance of responsibility for our personal health. The problem is a product of all of these elements, ongoing and growing.

Attached to this statement and in your files is a brief analysis of a growing uncompensated care impact on the Charleston Area Medical Center. These figures show that the impact that this problem is having on us and other providers throughout the country. A very quick review will show that in 1990 our hospital will write off 31.6 percent of its gross revenues to uncompensated care. That is not a misprint; 31.6 percent of the total charges will simply be written off as uncollectible.

The single greatest portion of that——

Chairman ROCKEFELLER. As I read that, that is a 12-percent increase in 4 years.

Mr. GOODWIN. From previous years, and in 4 years, it is about a 200-percent increase.

The single greatest portion of that is due to the reduced Medicare payments. You were a champion and you were very instrumental in reducing the attack upon health care providers in the 1990 budget, in terms of trying to protect the reimbursement and the benefits for people under the Medicare Program.

The new budget has just been produced, and I am sure you have seen the original drafts, calling for an $8.1 billion reduction in the 1991 budget for Medicare. Neither the providers nor our citizens can afford those kinds of reductions without tremendous acceleration of the problems that you heard expressed today in another hearing.

As State and Federal financing have become more and more restricted, costs are shifted to the private payor and to the insured. Business and third-party payers are reducing coverages and benefits. More and more people, both working and unemployed, are

finding themselves uncovered and unable to afford health care bills from their private income.

Bad debts and charity increases at the hospital and provider level and charges go up to cover the loss. As more people become uninsured and as coverages are reduced more, the cycle simply accelerates.

Whose problem is this? I submit that it is everyone's problem. Just as we cannot blame the problem on a single source, we cannot attack it by aiming at a single target. We cannot expect Government to simply pour in more money, we cannot expect business to shoulder the responsibility alone, we cannot expect providers to simply give more and more uncompensated care, and we certainly cannot expect our citizens to go without health care.

In the long term, we must work toward a clear, definitive national health policy. We cannot consider alternatives of national health insurance or a nationalized health care system without a clear national health policy.

You mentioned in your opening statement: "We are working without a blueprint." We must have a policy to guide us in the long term.

Questions unaddressed must be asked and must be addressed at the national level, questions related to what benefits are to be governmentally provided, what benefits under State and Federal programs. How should we integrate the governmentally provided services with the private sector? Will we decide that Government will provide certain health care benefits, with others to be purchased by those who have the means? Are we willing to continue to spend the majority of the Medicare and governmental dollars dedicated toward the last 6 months of our population's life or should we shift them to basic primary and preventative care on the front end? Can we afford both? Are providers to become agents of the Government or are providers under contract? Will we allow the malpractice lottery in this country to continue unabated?

Thinking of addressing all of these questions at once is almost, if not, literally overwhelming, yet can we afford to do otherwise?

I submit that one of the greatest contributions this Commission can make is to create an environment and a process whereby we can do exactly that, develop a well-thought and comprehensive national health policy. Without it, we will surely continue our present uncoordinated and confusing misdirection.

In the short run, I suggest several things that we can offer which will have some relief and will build a base for future changes. All of these, I am sure, are not going to be popular with many of my colleagues.

Current levels of funding for Medicare and Medicaid must be maintained with adequate inflationary increases. We simply cannot afford to let the system slip any further in terms of access to care because of inadequate financing.

Minimum levels of health care benefits should be required of all employers and incentives for pooling small employer risk created. Insurers must be required to offer adequate policy coverages which are clearly and simply explained to the citizen.

Limitations on punitive and pain and suffering damages must be imposed on malpractice litigations.

Health care institutions should be required to provide services for the indigent, at least proportionately to their market share, or contribute to funding such care.

Emphasis should be placed on primary services through restructuring of the Government payment system, and as you heard this morning, the bureaucratic processes which encumber access to and the delivery of health care must be identified and eliminated.

Demonstration projects designed to develop innovative ways to create access and deliver services for the poor and uninsured must be encouraged and supported through regulatory waivers and redirection of dollars.

Finally, I would suggest developing added financial assistance and incentives for educational programs which provide health care services to the poor and uninsured.

The challenges are monumental, the tasks are overwhelming, and we cannot apply simplistic solutions or attack only one segment of the problem. We must act on multiple fronts but with the understanding of how they relate and impact on each other.

I urge you to call for innovative action in each of the areas I have suggested, and in terms of the Pepper Commission's future role, I submit that it has the opportunity to become the focal point for future action to lead us toward the development of a definitive national health policy involving input from all segments of government, business, education, and the health care industry, and I would encourage you to make that a top priority for the continuation of the efforts of the Pepper Commission and to set a deadline, as you have in this cycle, to have that national health policy complete and in place by 1993.

Thank you very much. We certainly stand ready to assist in any way we can.

[The prepared statement of Mr. Goodwin follows:]

PEPPER COMMISSION HEARING
CHARLESTON, WEST VIRGINIA
DECEMBER 13, 1989

STATEMENT BY PHILLIP H. GOODWIN, PRESIDENT OF CHARLESTON AREA MEDICAL CENTER, INC.

'Senator Rockefeller! Members of the Commission. Welcome to Charleston and thank you for the opportunity to offer this statement for your deliberations. I am sure that in your hearings and research you are compiling reams of material and data regarding the issues related to health care for our citizens. I doubt that I can add much that is new or dramatic. My goal, therefore, is to emphasize the growing magnitude of this impending crisis and urge thoughtful and expedient actions.

We <u>are</u> facing <u>crisis</u> in health care in our country. We cannot wait for complete study and research to begin our responses. Approximately 35 million of our citizens are falling between the cracks of adequate resources to obtain health care!

The <u>problem</u> is not the <u>cost</u> of health care services! The problem is not <u>access</u> to health care! The <u>problem</u> is not who pays! The <u>problem</u> is not lifestyle and acceptance of responsibility for our personal health!

The problem <u>is</u> a product of <u>all</u> of these elements, ongoing and growing. Attached is a brief analysis of the growing uncompensated care impact on the Charleston Area Medical Center. These figures show the impact that this problem is having on us and all other health care providers. A quick review shows in 1990 our hospital will write off 31.6% of its gross revenue due to uncompensated

care. The single greatest portion of that is due to reduced Medicare payments. As state and federal financing has become more and more restricted, costs are "shifted" to the private payor and insured. Business and third-party payors are reducing coverages and benefits. More and more people, both working and unemployed, are finding themselves uncovered and unable to afford health care bills from their private incomes. Bad debts and charity increase and charges go up to cover the loss. As more people become uninsured and coverages are reduced, the cycle accelerates.

Whose problem is this? Everyone's! Just as we cannot blame the problem on a single source, we cannot attack it by aiming at a single target! We cannot expect the government to simply pour in more money. We cannot expect business to shoulder the total responsibility. We cannot expect providers to give more and more uncompensated care. We certainly cannot expect our citizens to go without health care.

In the long term, we must work towards a clear and definitive National Health Policy. We cannot consider alternatives of "National Health Insurance" or a "Nationalized Health Care System" without a clear National Health Policy.

Questions yet unaddressed must be asked and addressed at a national level. Questions related to what benefits are to be provided under state and federal programs? How should we integrate governmentally provided services and the private sector? Will we decide that the government will provide certain health care benefits with others to be purchased by those who have the means? Are we willing to continue to spend the majority of governmental

health care dollars in the last six months of our population's life or should we shift them to basic primary and preventative care? Can we afford to do both?

Are providers to become agents of the government or providers under contract? Will we allow the malpractice "lottery" to continue unabated? Thinking of addressing all of the questions at once is almost overwhelming. Yet, can we afford to do otherwise?

I submit that one of the greatest contributions this Commission can make is to create an environment and process whereby we can do exactly that! Develop a well thought and comprehensive National Health Policy. Without it we shall surely continue on our present uncoordinated, confusing misdirection.

In the short run I suggest several things which can offer some relief and build a base for future changes.

1. Current levels of funding for Medicare and Medicaid must be maintained with adequate inflationary increases.

2. Minimum levels of health care benefits should be required of all employers and incentives for pooling small employers' risk created.

3. Insurers must be required to offer adequate policy coverages clearly and simply explained.

4. Limitations on punitive and pain and suffering damages must be imposed on malpractice litigations.

5. Health care institutions should be required to provide services for the indigent at least proportionally to their market shares or contribute to funding such care.

6. Emphasis should be placed on primary services through

government payment structuring.

7. Bureaucratic processes which incumber access to and delivery of health care services must be identified and eliminated.

8. Demonstration projects designed to develop innovative ways to create access and deliver services for the poor and uninsured must be encouraged and supported through regulatory waivers and redirection of dollars.

9. Develop added financial assistance for educational programs which provide health care services to the poor and uninsured.

The challenge is monumental. The tasks overwhelming, but we must begin now to address them. We cannot apply simplistic solutions or attack only one segment of the problem. We must act on multiple fronts, but with understanding of how they relate to and impact each other.

I urge you to call for innovative action in each of the areas suggested and to make the development of a National Health Policy involving input from all segments of the government, business, education and the health care industry, a top priority to be completed by the end of 1993.

Thank you.

Phillip H. Goodwin, F.A.C.H.E.
President
Charleston Area Medical Center, Inc.

attachments

CHARLESTON AREA MEDICAL CENTER, INC.

MISCELLANEOUS FINANCIAL INFORMATION

DECEMBER 4, 1989

($000)

	1986	1987	1988	Projected 1989	Budget 1990
Gross Patient Revenues	$198,174	$230,248	$272,930	$301,409	$330,630
Stated Price Increases	8.0%	--- 17.9% thru 10/1/87 ---		7.0%	5.8%
Operating Expenses	$158,803	$181,763	$192,616	$203,295	$220,901
YTD Percent Increase	12.9%	14.4%	5.9%	6.7%	8.7%
Uncompensated Care	$39,505	$57,790	$76,223	$91,955	$104,592
YTD Percent Increase	60.0%	46.0%	32.0%	25.0%	13.7%
Bottom Line	$8,211	$1,025	$12,752	$12,664	$11,714
Percent of Gross Revenues	4.1%	.4%	4.7%	3.6%	3.5%

CHARLESTON AREA MEDICAL CENTER
1990 PROPOSED OPERATING BUDGET

CONTRACTUAL ALLOWANCE, CHARITY, AND BAD DEBT EXPENSE
PER EQUIVALENT PATIENT DAY
FOR 1986 THROUGH 1989 PROPOSED OPERATING BUDGET

	1986	1987	1988	1989 Projected	1990 Budget
EQUIVALENT PATIENT DAYS	290,593	301,925	293,940	271,474	279,123
Gross Patient Revenue	$ 681.96	$ 719.73	$ 929.57	$1,110.57	$1,184.53
Charity	$ 30.92	$ 31.77	$ 42.45	$ 47.75	$ 50.93
Bad Debt	33.18	30.27	45.14	51.09	54.49
Subtotal	64.10	62.04	87.59	98.84	105.42
Medicare Subsidy	53.25	79.27	129.17	183.36	199.53
Medicaid Subsidy	13.02	15.06	32.55	44.48	48.69
Other	3.41	1.77	9.85	12.04	21.07
Subtotal	69.67	96.10	171.73	239.88	269.29
TOTAL	$ 133.77	$ 158.14	$ 259.32	$ 338.72	$ 374.71
Contractual Allowances, Charity, and Bad Debts % of Gross Patient Revenue	19.6%	21.9%	27.9%	30.5%	31.6%

CHARLESTON AREA MEDICAL CENTER, INC.

MEDICARE CONTRACTUAL ALLOWANCES

	1988	Projected 1989	Budgeted 1990
INPATIENT			
Total Charges	$99,750,669	$107,573,396	$121,107,948
Total Payments	61,246,361	63,119,626	71,131,798
Contractual Allowance	$38,504,308	$ 44,153,770	$ 49,976,150
Percentage	38.60%	41.32%	41.26%
OUTPATIENT			
Total Charges	$ 5,459,019	$ 9,262,804	$ 13,443,675
Total Payments	3,378,542	5,427,938	7,100,095
Contractual Allowance	$ 2,080,477	$ 3,834,866	$ 6,343,580
Percentage	38.11%	41.40%	47.18%

Chairman ROCKEFELLER. Thank you very much. Dr. Latos.

STATEMENT OF DR. DERRICK LATOS, PRESIDENT, WEST VIRGINIA MEDICAL SOCIETY

Dr. LATOS. Senator Rockefeller, it is always a pleasure and an honor to be able to speak with you, and again, welcome back home.

My comments to you are being offered on behalf of the West Virginia State Medical Association of which I am president. However, and just as importantly, I am speaking as a practicing physician directly involved in the care of patients for nearly 20 years, most of that in West Virginia.

The role that you are assuming as chairman of the prestigious Pepper Commission is vital since the health care of millions of American citizens, those living today and those to be born over the next several years, will depend upon the decisions and recommendations that you and this Commission will make.

Hopefully, the testimony you hear today, along with that already given during previous hearings such as this, will give you the information you need to make these comprehensive choices.

Providing medical care for those in need has been a basic tenet of the medical profession for hundreds of years. Only in recent times has the issue of uninsured care come into question. By and large, those individuals who have required care have received it. The multitiered health care system we have in the United States is not unique to this country.

However, many of the concerns facing us today are directly attributable to the advances in medical science, generated largely by American health care technology. While data suggests that certain measures of success of a health care system, such as longevity and infant mortality, may be better in other nations than in the United States, many facets of health care readily accessible and in high demand by our citizens are not even available in other industrialized societies.

Highly technical home health care programs and long-term care facilities with physical therapy and other rehabilitative services are only a few examples.

The main arguments seem to center around the feeling that not everyone has equal access to this care, and that our health care costs more to provide than we are willing to pay for it. We must remember that whether we are discussing automotive production, nuclear technology, or health care, there can be no free ride.

I would like to focus on one area that this Commission is analyzing, and that is the problem of uninsured health care. First, it is essential to understand that of the 37 million Americans who are said to have inadequate or no health insurance, a substantial number whose annual income exceeds $20,000 choose not to make health care insurance a priority. To a large degree, these are persons whose employers do not provide health care benefits as part of their employment benefit package.

They subsequently choose not to use discretionary income for health care insurance. Whether they are eligible for public-funded programs such as Medicaid varies tremendously from one State to another, and to the extent that those ineligible for such programs

comprise an increasing proportion of the population, the burden of paying for their care is shouldered variably by larger employers and the private sector insurance programs.

This is balanced by the need for those providing health care services to do so at costs greater than the levels of reimbursement. Thus, the cry for the reform in our health care system has taken the form of national health insurance, in which everyone would have presumed equal access to care, yet no consensus has been reached as to exactly how we are going to pay for this.

A State such as West Virginia provides an opportunity to gain excellent insight into some of these concerns. As a State with one of the highest unemployment rates in the United States, our citizens have similarly high rates for many debilitating and fatal diseases.

As job layoffs increase because factories and companies close, the number of persons eligible for any health care insurance, including Medicaid, decreases. This is compounded by the fact that Medicaid reimbursement in West Virginia is substantially lower than in surrounding States.

However, like the song "How are things in Glockamorra?" all is not bad here in West Virginia. I am very proud to tell you that I agree with comments made earlier, that we have made tremendous strides in developing new programs to improve access to care for those who cannot afford to pay for it, and we as physicians are enthusiastic about the opportunity to work with our legislatures and government, both State and Federal, to plan for the future health care and medical education of our citizens.

We in West Virginia are not looking for a handout from the Federal Government. We are hopeful that meaningful revision of the Medicaid Program will provide greater flexibility to allow innovative programs that may, of necessity, vary from one State to another.

We should, however, strive to provide uniform, adequate benefits for all of the poor. I would l like to offer a few additional recommendations for your consideration.

All employed Americans must have health care benefits. The use of State risk pools, as has previously been suggested, may be very helpful here.

Older persons, especially those of limited financial resources, must have continued access to acute and long-term care. A revised system should not define eligibility simply as an entitlement program, but rather on the basis of need, retaining patient incentives to minimize overutilization.

A variety of health care systems will maintain choice and competition in health care, and should reduce the administrative burdens on Government and other health care insurers.

Finally, reformation of the professional liability system will reduce the higher costs associated with defensive medicine. This will result in additional revenue sources which can be used to develop preventive care programs, especially to the uninsured, which, in turn, will result in a healthier population who will require less health care.

I would like to reaffirm that my profession has a tradition of providing free care to those who cannot afford it, at least until Con-

gress takes the needed actions to eliminate financial barriers to appropriate medical care for the uninsured and the needy.

Senator Rockefeller, I have minimized my comments. You have the full text in front of you, which I am sure you will enjoy reading on the way back to Washington.

Once again, thank you for this opportunity, sir.

[The prepared statement of Dr. Latos follows:]

Comments - Pepper Commission
Derrick L. Latos, MD
December 13, 1989
Charleston, WV

My comments to you are being offered on behalf of the West Virginia State Medical Association of which I am President. However, and just as importantly, I am speaking as a practicing physician directly involved in patient care for nearly 20 years, most of that in West Virginia.

The roles you are assuming as members of the prestigious Pepper Commission are vital, since the health care of millions of American citizens--those living today and those to be born over the next several years--will depend upon the decisions and recommendations you make. Hopefully, the testimony you hear today along with that already given during previous hearings such as this, will give you the information you need to make these comprehensive choices.

Providing medical care for those in need has been a basic tenet of the medical profession for hundreds of years. Only in recent times has the issue of uninsured care come into question. By and large, those individuals who have required care have received it. The multi-tiered health care system we have in the United States is not unique to this country. However, many of the concerns facing us today are directly attributable to the advances in medical science, generated largely by American health care technology. While data suggest that certain measures of success of a health care system such as longevity and infant mortality may be better in other nations than in the United States, many facets of health care readily accessible and in high demand by our citizens are not even available in other industrialized societies. Highly technical home health care programs and long term care facilities with physical therapy and other

rehabilitative services are only a few examples.

The main arguments center around the feeling that not everyone has equal access to this care, and that our health care costs more to provide than we are willing to pay for it. We must remember that whether we are discussing automotive production, nuclear technology--or health care--there can be no free ride.

I would like to focus on one area that this Commission is analyzing--that is the problem of uninsured health care. First, it is essential to understand that of the 37 million Americans who are said to have inadequate or no health insurance, a substantial number whose annual income exceeds $20,000 choose not to make health care insurance a priority. To a large degree, these are persons whose employers do not provide health care benefits as part of their employment benefit package. They subsequently choose not to use discretionary income for health care insurance. Whether they are eligible for public-funded programs such as Medicaid varies tremendously from one state to another. And to the extent that those ineligible for such programs comprise an increasing proportion of the population, the burden of paying for their care is shouldered variably by larger employers and the private sector insurance programs. This is balanced by the need for those providing health care services to do so at costs greater than the levels of reimbursement. Thus, the cry for the reform in our health care system has taken the form of national health insurance, in which everyone would have presumed equal access to care (but no consensus has yet been reached as to how to pay for it).

Revising the methodology for paying physicians with stronger emphasis on appropriateness of care and an eye focused on volume of services has recently been

enacted by Congress. While this part of the budget reconciliation bill is an important step in the right direction for improving access to primary health care services, it still fails to completely address the problems of the underinsured.

A State such as West Virginia provides an opportunity to gain excellent insight into some of these concerns. As a state with one of the highest unemployment rates in the U.S., our citizens have similarly high rates for many debilitating and fatal diseases. As job layoffs increase because factories and companies close, the number of persons eligible for any health care insurance, including Medicaid, decreases. This is compounded by the fact that Medicaid reimbursement in West Virginia is substantially lower than in surrounding states.

The litigious climate prevalent in an area of high unemployment, the lack of large metropolitan centers, increasingly regulatory health care policies, and the entirety of physicians payment inequities disfavoring rural practice are all responsible for the difficulty we are experiencing in retaining and recruiting physicians to practice in West Virginia. So far this year, we have seen a net loss of approximately 80 physicians. Currently, less than a dozen family practitioners are delivering babies in West Virginia, in contrast to 100 who did so ten years ago. Fewer and fewer board-certified obstetricians are available to deliver babies of our high-risk mothers, a majority of whom are from among the under or uninsured. Nearly sixty percent of West Virginia births last year occurred in mothers receiving Medicaid.

West Virginia physicians have also seen a dramatic increase in discounted contractual fee arrangements, such as exists with HMOs, PPOs and other managed care programs. When Medicaid and even Medicare payments are delayed by lack of

funds or other administrative tactics, devastating effects are often seen, especially for solo practitioners or others with high fixed overhead costs that must be paid. A recent survey indicates that West Virginia physicians have provided some $142 million worth of uncompensated care last year. This means that 25 percent of physicians' care was provided free. It is speculative to think that this practice can increase or last indefinitely.

A physician who must borrow money to meet expenses may be a welcome client for the local banker, but a physician who relocates or closes his office creates a great economic loss for his community.

When a major private payor such as the state of West Virginia--which provides health insurance coverage for nearly 225,000 persons (12 percent of the West Virginia population) fails, delays, or discounts its payment to providers, the situation is even worse.

However, like the song, "How are things in Glocca Morra,"--all is not bad here in West Virginia.

We have made great strides in developing new programs to improve access to care for those who cannot afford to pay for it. We physicians are enthusiastic about the opportunity to work closely with our legislators and state government to plan for the future health care and medical education of our citizens.

We in West Virginia are not looking for a handout from the federal government. We are hopeful that meaningful revision of the Medicaid program will provide greater flexibility to allow innovative programs that may, of necessity, vary from one state to another. We should, however, strive to provide uniform, adequate benefits for all of

the poor. I would like to offer a few additional recommendations for your consideration.

All employed Americans must have health care benefits; the use of state risk pools may be very helpful here.

Older persons, especially those of limited financial resources, must have continued access to acute and long term care. A revised system should not define eligibility as an entitlement program, but rather on the basis of need, retaining patients' incentives to minimize over-utilization.

A variety of health care systems will maintain choice and competition in health care, and should reduce the administrative burdens on government and other health care insurers.

Finally, reformation of the professional liability system will reduce the higher costs associated with defensive medicine. This will result in additional revenue sources to which can be used to develop preventive care programs, especially to the uninsured, which will in turn, result in a healthier population who will require less health care.

I would like to reaffirm that my profession has a tradition of providing care free of charge to those who cannot afford it, until Congress takes the needed actions to eliminate financial barriers to appropriate medical care for the uninsured and needy.

Chairman ROCKEFELLER. Thank you, Dr. Latos.

Let me ask Phil Goodwin a question to start off here. The question of uncompensated care is gigantic. It is so not only in this State but all across the country. If we had a system wherein everybody had at least basic access to health care, would that help uncompensated care as much as I would like to think it would or would it only be a partial answer?

Mr. GOODWIN. That is a difficult question to answer in a very short period of time but I will try to attack it from two brief standpoints.

There is no question that we need a system that offers access to everybody at the appropriate point of entry. It would not be of benefit to us if that access was difficult to get to, if that access was in the wrong delivery method and so forth, and it would not necessarily be beneficial from a cost standpoint if there was not a funding mechanism to pay for that access.

One of the problems we have with the Medicare Program now is that we tell the people who are eligible for Medicare: "The system is accessible to you; go and use it," and when it is used, the reimbursement is inadequate to pay the cost and that cost gets shifted to the rest of the population, so it is a two-prong problem.

We definitely need to improve the access, principally in the primary and preventive areas, and find funding to give people the means to get primary care, prenatal care, preventive care, to encourage education in nutrition and housing, and so forth. There is no question that those dollars spent on the front end would save considerable dollars on the acute side.

The other part of that is once we create that system, there has to be an adequate source to fund that. We simply cannot create shells, send people for service and then not support it financially.

Chairman ROCKEFELLER. You bring up the question of prenatal care. I have another hat, which I am not wearing now—I am Chairman of the National Commission on Children. We were in Chicago several weeks ago at Cook County General Hospital and then I was up at Ruby Memorial in Morgantown, looking at their neonatal intensive care units for children. As you said, Taunja, I think West Virginia has a high rate of teenage pregnancy. In Chicago, a lot of the pregnancies are not only by teenagers, but they are by teenagers who are doing crack and cocaine, so the result is 1½-, 2-, 2½-pound babies.

It is extraordinary to me the difference that is made if we could make sure these girls and women get prenatal care, starting in the first trimester. Let's say that care costs perhaps $400, $500, $600, as opposed to the cost if they do not get the care in the first, second, third trimesters or at all. Your baby ends up in Cook County or here or some other neonatal unit at 2½ pounds, probably with substantial cognitive disabilities and probably some fairly severe physical ones too. I understand that the costs go to $1,500 a day.

So you compare the $600, let's say for good prenatal care, nutrition, all the rest of it. Or the baby has to stay at the hospital for 2, 3, or 4 months, costing $300,000, $400,000, $500,000, $600,000. Then when that low birth-weight baby gets out, the baby is probably going to be scarred for the rest of his or her life.

It is the most extraordinary mathematical proof of how stupid we can be in this country. If we could get people to receive prenatal care and if we would put resources into prenatal care, an incredible amount of public money could be saved. It is the right human thing to do. It just boggles my mind to see the connection between a $600 investment on the one hand and the half a million dollars of costs that can happen from not making that investment.

Mr. GOODWIN. With your permission, I would reiterate one of the comments in my opening statement and that is, that is not a Chicago problem. You might be shocked to find the extent that problem does exist in West Virginia and in Charleston, WV.

When you have been a participant and a visitor at Women & Children's Hospital, you know a lot of those folks over there. We see those cases every day. In fact, approximately 40 percent of the newborn infants that we see at Women & Children's Hospital are high risk or low birth weight of some kind.

They are not necessarily as attributable to the crack, cocaine problem, though that problem does exist in our community, but they do come from the same sources of poor prenatal care, poor nutrition, poor education in terms of how to take care of myself and my baby, and that problem exists throughout this State and the numbers are identical.

If we spent the money on the front end and put the resources where people could get to them—it is one thing for us to have a family resource center at Women & Children's but if that resource is not available in the local community at an early date—we never see them until a very late period of time.

So you are exactly right. If we can get that revenue directed toward the local community for prevention and for care and for education, it will save tremendous dollars.

Chairman ROCKEFELLER. I believe we are going to hear about that from Dr. Bob Walker who is on the next panel.

Let me ask a question of all of you, and I might start with you, Taunja. In the Pepper Commission we are looking at access to care and long-term care. Now, I met 1 month, 2 months ago with 11 Governors, 11 hostile Governors, who said: "We don't want to pay one dime's more money for health care. We are fed up with it. We are fed up with the way you Federal people keep shifting burdens onto us and we are here to tell you that we don't want anymore."

I got the message loud and clear and I gave back a message loud and clear, saying: "Look, you are broke, we are broke, the American people are broke. A lot of people do not have access to health care. We have got to do our job. Nobody can get off." As either Rick or Phil said: "There is no free ride for nobody. We are all going to have to suffer somehow through this process, including beneficiaries. Everybody is going to have to suffer."

Now, if you wanted to give the State responsibility let's say for either long-term care or access and the Federal Government basic responsibility for long-term care or access. You could make an argument that access to health care belongs sensibly in the hands of the Federal Government. And then you could also make an argument that long-term care, although both the Federal and the State would have to share in the financing of it, is probably more proper-

ly administered by the State because States have more experience in long-term care.

Is that a reasonable division of labor, so to speak, as I presented to you, or would you have comments on that?

Ms. WILLIS-MILLER. Dr. Brown is a revered member of our department. He can speak on that.

Dr. BROWN. I think the role of the Federal Government, Senator Rockefeller, has to be a lead, moral articulator of broad mandates provided with a sense of focus and direction nationally. On the other hand, I believe I would agree with your statement that the States are the appropriate administrative arena.

I do believe that States, however, have to carefully examine their own administrative structure, management practice, service delivery systems, and maybe we need to be forced to do this, to adequately address the long-term care challenge ahead.

I do not think we can adequately address it if we are involved in fragmentation, a lack of sense of direction, a lack of clear commitment and well thought-out goals and agencies that are not willing to work together toward common ends.

Chairman ROCKEFELLER. Does anybody else want to take a crack at that? Phil.

Mr. GOODWIN. I think that the scenario in terms of administering the State versus Federal government is an accurate one and probably should be left as it is. But I think that the problem is much, much deeper than that and I would go back to my comment again, I think the focus point eventually has got to be a national health policy in terms of what at the Federal Government level do we want to mandate is going to be accessible to our people in terms of long-term care, and we must broaden the definition of long-term care.

We have got to stop stacking our old people like cordwood in nursing homes and start addressing the issue of inhome services, of home care, of day care, of respite care and so forth because we are wasting a lot of dollars on people who do not belong in nursing home institutions, and I am not knocking the nursing home industry, it is just not the way to deal with the total problem.

So I would say two things: You have to really address the scope of where and how we are going to deliver services but first we have to determine, what is the Federal Government willing to provide as a basic service, what is the State then willing to provide as a secondary service, and what is the public then expected to pay for out of their own private means. Until we define those questions, we are going to be in this morass of pointing fingers about whose responsibility or who is failing in the system.

Dr. BROWN. I think I would echo everything Phil just said and expand just very briefly. I agree completely that the Federal Government ought to be in the position of developing and promoting the health policy for this country——

Chairman ROCKEFELLER. Including minimum standards?

Dr. BROWN. Absolutely. The definition is difficult to reach; in other words, what is the minimum standard that is reasonable? The Federal Government will clearly be involved in paying for some of this and that is where the States will receive whatever Federal support financially that they are going to receive. But I

think that we also need to have, in effect, a lesser degree of controls and shackles from the Federal side, to allow the States to run the operations that meet their very diverse regional identities.

Minnesota has very different priorities and needs than does West Virginia and certainly, ghetto New York City is different than Lincoln County, WV. If there is a law or a policy coming out of Washington that tries to make all of those equal, it will never work. What I have asked for and I think what Taunja has said too is that we need relief from the centralized control of the Federal Government. Let the States handle that, but I agree with Phil that the baselines really ought to be defined at the Federal level, and I would go one step further——

Chairman ROCKEFELLER. Funded or defined?

Dr. BROWN. Defined. There will be some mandatory funding that has to come. As I pointed out, West Virginians, I don't think, want a handout from the Federal Government. Of course, we would like that, but we have got to realize that we must depend on our own resources. As individuals and, I think, the creativity of the persons in this country and in West Virginia, we will be productive enough to make due with what we need to get.

Chairman ROCKEFELLER. The dilemma is when you get the Federal Government saying: "There are going to be some basic standards to which you are going to have to adhere." Then people at the State level say: "Now, wait a second. If you expect us to participate, we have got a right to set the rules." When you are talking about access to care and long-term care, there have got to be certain standards which are set.

The States may be unhappy. I just almost think that if you are talking about basic minimum standards, the States can build on those if they want. You have to have the Federal Government giving direction on that.

Taunja, do you have a problem with that?

Ms. WILLIS-MILLER. Senator, I do not have a particular problem. I would like to think about it a little more. I guess I have to say that I understand the perspective of those States that want flexibility, and I know that you have been supportive in some of those areas. For instance, the Medicaid Waiver Program would certainly be much easier if we did not have a waiver to go through. If we were just able to administer a long-term care program, I do not think we would have any problems if that long-term care program were required to meet certain standards, but it certainly would be easier if we then were allowed to kind of figure out exactly how we got to those certain standards.

I think that conceptually I am in agreement that the Federal Government should set some basic standards. I think that is necessary. I guess I am not quite as definite with respect to who should fund what, and that is something on which I do not have an opinion and perhaps it is because I have spent so much time recently trying to come up with the State's share of that.

Chairman ROCKEFELLER. Phil, another question for you. Obviously, when you get down to access of care, you are talking about the business now. Eighty percent of the people do have health insurance; 80 percent who do not, incidentally, do work full time, which is interesting.

We now get to the question of the role of business. You come out, I think, fairly clearly for some sort of mandated benefits system. We have the problem of smaller businesses, industries of 25 employees or fewer, 10 or fewer, even 5 employees who could have real problems with such mandates and who may be violently against them.

There is the alternative of offering some kind of subsidy or tax incentive to help small businesses comply. Is it your view that business basically has to continue its role in providing health insurance or else the whole burden gets shifted onto the public, which means the taxpayer?

Mr. GOODWIN. No question about it, and it is getting shifted over both on business and on the public right now. I understand that this is most controversial and I understand that it would take some study to figure out the appropriate formulas.

I think, though, that it is not enough simply to say you have to provide a minimum level of benefits as employers. I think there have to be perhaps tax credit incentives, perhaps there should be mandated statewide risk pooling. When you simply leave it to the industry and say: "You have got to provide this" and we do not change the way in which insurance companies have to approach this problem, then these small employers are faced with $1,000 per person premium, which is a ridiculous scenario to put on a small business.

So I think we have to look at it and say: "If you are going to do business as an insurance company, you have to provide this, and companies that practice or provide those services in a State have to come together in terms of risk pooling. You have to create a mechanism perhaps with the State where small employers can pool their risks. You can go into a common risk pool big enough to spread that risk and actually be able to bring those premiums to an affordable level."

The way they are right now, it is all experienced rating or self-insurance and no single small employer can afford to do that. So we have got to find mechanisms to pool that risk, and if we do, I think something can be accomplished.

Chairman ROCKEFELLER. One of the things that I really look forward to, in fact, is working with the insurance industry, hopefully cooperatively, to reform the way they do business. That is an industry which has undergone unbelievable change, not necessarily helpful change in terms of the effect on people with health care problems.

Frankly, I think the insurance industry knows that they are going to have to make reforms and I think they know that they can make reforms and still survive. But that is going to be a tough one.

Dave, let me give one question for you and then we are going to go on to the next panel, unless you have other comments that you want to make.

You referred to case management and, obviously, it is a very crucial concept in all of this. Do you think the case managers ought to have special qualifications or do you think that certain educational levels will do the job? When you think about a case manager for

the future, who are you thinking about, what kind of qualifications?

Dr. BROWN. I am thinking of certified professionals I sure am.

Chairman ROCKEFELLER. What kinds of people would those have to be?

Dr. BROWN. I think people with experience in social work, similar type of degrees. That is not to say that there are not a lot of good folks in our aging network with a lot of on-the-job training who would make excellent case managers, but I would like to see them certified, very definitely, before they lay hands on long-term care clients. I think the State, or perhaps even the Federal Government, can set some standard of certification for professionals in long-term care.

Chairman ROCKEFELLER. Rick, let me ask you a question. Defensive medicine and medical liability problems are big issues. Generally speaking, physicians try to do the right thing. They do not want to get sued. I gather they may practice defensive medicine because of medical liability problems, which means they do more procedures than they would otherwise choose to do.

Physicians sometimes say that all of the unnecessary procedures which they do are because they are practicing defensive medicine. The Rand Corp. says that 30 percent of doctors' procedures are neither appropriate nor medically necessary, depending upon what you are talking about. The AMA [American Medical Association] has been looking at that question, and I think most people agree.

How much of the excess in physician procedures do you think is related to defensive medicine, which, in turn, stems from our medical liability system, and do you think there is some part which is beyond that?

Dr. LATOS. Yes, depending upon which specialty in which one practices and in what part of the country one lives. I would think that 15 years ago it constituted a very small quantity in terms of the dollar amount and the number of procedures. But today, I would venture a higher estimate.

Based on my own practice and those of other physicians in West Virginia, there is probably a minimum of 25 percent of not only the volume of services but in some cases, the expensive care that we order that can be attributed to "defensive medicine." Many diagnostic tests, for example, are done because of requests by the patient. There is often an implied threat that if the requested test is not done, and if a good result does not occur, there will be some subsequent action threatened or even taken.

Not all of that 25 percent is purely for defensive medicine purposes. You alluded to the point of appropriateness. Physicians are frequently in controversy as to the relative value of a given procedure in terms of how helpful it may be in taking care of an individual patient. That is an area which is under tight scrutiny right now, and I think within the next few years we will have a better handle on that, as practice parameters become fully developed.

The best example I can give you is the use of certain diagnostic studies that some physicians sincerely believe are necessary in order to give the best care for an individual patient. To be able to tell Mr. Jones with a 99 percent certainty that he does not have a brain tumor, a physician may order a number of studies. Another

physician may say: "I do not need that test because I just feel that you don't have that brain tumor and, therefore, we are not going to order it."

That is not really a defensive medicine approach, but there is clearly a wide variation among clinical skills that physicians use. However, they must have the freedom to use technological support because patients require different amounts of security that is only provided by multiple tests.

Now, if we were in London, we might not be able to order an extensive battery of diagnostic studies. In the United States, we have developed the ability to provide a wide variety of services tailored to the individual basis.

One of the difficulties with practice guidelines is that we cannot afford to have our patients treated by a cookbook approach. I must retain the ability to look my patient in the eye and develop an understanding of his or her concerns and degree of insecurity, and then provide the care that I feel is best suited for the situation.

Chairman ROCKEFELLER. Time is running. There are lots of things I would like to discuss but we have got to go on to the next panel. I really thank all four or you for being here, for your very, very significant contributions. Thanks a lot.

Panel 4: Dr. Robert Walker, chairman, Department of Family and Community Health, Marshall University Medical School. Patricia Holmes White, Health Right of West Virginia. Earl Jarvis, director of Aging Programs, PRIDE of Logan County. Dr. Walker.

STATEMENT OF DR. ROBERT WALKER, CHAIRMAN, DEPARTMENT OF FAMILY AND COMMUNITY HEALTH, MARSHALL UNIVERSITY MEDICAL SCHOOL

Dr. WALKER. I want to just describe a program that we have implemented in Lincoln County for care of the rural elderly. This is a program that jointly—it is a partnership, really, between Marshall University School of Medicine, Lincoln Primary Care Center, which is a community owned and operated primary care complex in Hamlin, and the Benedum Foundation, who provides the funding and some technical support for the project.

What we wanted to do was look at really kind of a new method of delivery, health care delivery, that assured, first of all, or guaranteed, protection of the chosen lifestyle of rural people. Second, that it at least contained cost, if not actually attempted to save money over the annual expenditure for the care; that guaranteed continuity with a provider with special education in geriatrics, a special interest in it, a special sensitivity to it; and also a program that looked at the things we thought were very neglected in the rural elderly: prevention, for prevention in many aspects but also extending to environmental health, falls, safety, nutrition.

A lot of the nutritional problems with the rural elderly involve dental status: people trying to maintain their nutrition when they have no teeth and do not have dentures or do not have effective dentures.

We looked at psychological factors, especially depression and early dementia, and then looked at containing chronic disease,

taking excellent, "state of the art" care of chronic conditions, and acute conditions, too, when possible.

What we came up with in that framework was a program in which we use nurse practitioners and physician's assistants. Gave them special training in geriatrics, they then were assigned to a panel of patients in a fairly isolated part of the State. There are 20-some thousand people in Lincoln and the largest city is Hamlin with a population of 900, so we have got a pretty homogeneously diffused population.

We offered a lot of this care at home. We first completed an in-depth assessment: physical, mental, social, and environmental; tried to correct obvious problems in safety and environment; then, in cooperation with the primary care physician who worked with them, created a health plan for each participant that took into account their individual needs, risks, resources, and so on.

This plan was shared with the patient and shared with the patient's family, with patient approval, and the health plan was monitored, changed, adapted as need be.

Above the level of who we call the geriatric clinicians (who are geriatric nurse practitioners and physician's assistants), and the primary care doctors, who are mainly family doctors (in some cases internists, there is a support network of other specialists), nutritionists, safety experts, home economists, and so on, who are available but rarely see the patient. In other words, they are there to consult with the team and offer expertise when there were problems in the health plan or special problems that the team did not understand.

A majority of the care is given at home. We found out that elderly people will often allow disease to get very advanced before they show up in care, and then with the lack of physical adaptability that comes with age, the problem cannot be dealt with as successfully.

We tried to see people first, before new disease occurred, before serious medical problems occurred, and look for indicators that suggested intervention in some way. That intervention was designed to be at home where possible. Sometimes it occurs at the primary care center, sometimes it is in referral to Huntington or Charleston. Sometimes it means specialists traveling to Hamlin at least 1 day a month, at which time the participants are scheduled to see them.

The program also encourages mobility, rehabilitation, social support, and matching people with resources that are already in the community.

An underlying goal of this whole program is to prevent unwanted institutionalization. You have heard that already, but I think it is a real tragedy that we are paying top dollar for misery. We are paying top dollar, especially in the rural elderly that I know, for people to be sent miles away from their homes, families, friends, and communities.

Just at the time when their need for social support and human support is the greatest, they have it the least. They are in a very scientific setting but not a setting they would choose to live their lives in, almost to a person. For this, we are paying enormously.

We try to keep these people in their communities, in their homes, maximize their health, and stress prevention, which is not a concept often applied to elderly people.

We have also found that we need actually to reduce numbers of medicines as often as we need to add medicines. There is often a tremendous amount of unnecessary medication. Rural providers without this type of program are already hopelessly overworked, seeing 50 to 60 people a day, and when a frail elderly person comes in with 15 new problems, giving them the hour of time they may need is just impossible. Elderly patients often get a prescription instead of an indepth interview. It is no one's fault, it is just that providers often cannot deal with that need.

We are also developing computer software, which is fairly inexpensive, that would alert doctors to changes in status, following a good baseline. We are finding that there are indicators that will call for intervention that can prevent many of the worst problems.

The other thing we do with all of our participants is contact them at least every other week. That contact may be by phone, it may be in person, but there is a contact every other week to feed into the tracking system.

I think I am going to stop there. The program has only been going a year. We think it will save money. It is not hard to save money in this situation because if you can delay or prevent unwanted nursing home placement, you can save enough money to pay many times over for these kind of programs. I think it is cost-effective.

I think we really need to look at some innovative programs that give personal care, often in the home, to elderly people, especially isolated rural elderly people. We do not save money in the long run by not doing that. We just delay it. Just like the neonatal care, we end up saving a dollar here, paying $5 there, and failing to prevent the misery that occurs at the same time.

Chairman ROCKEFELLER. Lincoln County also, as I recall, ranks below the State in low birth-weight babies. You used to be far above it and I think now you are below it, partly because of problems that prevent women from getting prenatal care. We talked about that when I was out at your center. Your clinic is a friendly place, not a hostile environment. Therefore, women are more likely to come to you. Therefore, you attract people who would never come let's say to a large hospital or to some other place.

I applaud your efforts. It is extraordinary to be there and see what goes on there. Dr. Bob Walker is an extraordinary person.

Now you, Pat.

STATEMENT OF PATRICIA H. WHITE, ADMINISTRATOR, HEALTH RIGHT OF WEST VIRGINIA

Ms. WHITE. Good afternoon. I am Pat White and I am the administrator for West Virginia Health Right and a third-term member of the West Virginia House of Delegates.

Health Right is a free primary care clinic serving individuals and families whose income falls below the Federal poverty level, they do not have health care insurance and they cannot have Medicaid coverage.

The clinic is a free-standing clinic. It provides diagnosis, treatment, lab and x rays, medications, and referral services. All of the services that are provided at the clinic are at no cost to the patient or to the clinic itself in terms of our support coming in from the private sector.

The clinic's annual operating budget is less than $200,000 and it functions with a small paid staff which includes a nurse practitioner. Dr. Walker and I strongly agree about allied health professionals, certainly our saving grace in West Virginia. Our nurse practitioner provides the majority of patient care under established medical protocol.

In addition, the clinic has a large volunteer force of physicians, nurses, lab techs, pharmacists, and office personnel. There are about 250 volunteers.

Health Right, is a private, nonprofit, charitable corporation which is strongly supported by this community. The three Charleston area hospitals provide services to the clinic and the patients we serve. The medical community provides a large number of volunteers and physical specialists who have agreed to accept referrals of our patients into their practice without charge to the patient or the clinic.

The drug manufacturing representatives that provide physician's samples have strongly supported us and provide the clinic with the vast majority of medications that were dispensed. Last year, in fact, the clinic gave away over 2 million dollars' worth of medications and that was for 3,000 patients for approximately 10,000 clinic visits.

Health Right follows patients for chronic and acute care medical problems. Our patients diagnosis are no different than the general population, but they do put off their medical care longer. This delay in seeking medical care is because they do not have the resources to pay for care and makes their diagnosis more serious. They are not only hypertensive, they are severely hypertensive.

Today I hope to provide you with some insight into access problems of the uninsured and barriers they face and some recommendations to address the barriers.

As you are undoubtedly aware, there is a growing number of individuals without access to health care, and West Virginia is no different than the rest of the Nation in that, but unlike a decade ago, over 90 percent of the medical diagnoses today are for chronic illness and yet the majority of our health care resources are channeled into acute care.

Acute care facilities are neither designed, equipped, nor staffed to deal with long-term chronic illness. The health care delivery system needs to redirect its emphasis to deal with chronic illness, in a primary care setting, much earlier. This must include providing medications to treat chronic disease, thereby decreasing the need for inpatient care.

As you are aware and you have heard discussed today, hospitals are the major providers of charity care. This is neither cost-effective, medically sound, or good health policy. However, when individuals cannot afford primary care or continued medical care for chronic conditions, such as medications, they will inevitably end up in an acute care setting.

The individual is stabilized, then discharged, only to find themselves again without the resources to control their chronic illness and the cycle begins anew. With chronic illness, an individual's health condition deteriorates with each round of this cycle.

Our payment system at the Federal and the State levels have encouraged and even perpetuated this inefficient and very costly system with cost shifting to third-party payers. Not too surprisingly, the private sector has gotten wise to the cost shift and with Federal encouragement, most large companies are now able to prevent the cost shift, thereby reducing the numbers of payers sharing the cost of the charity care, which drives up their cost, perpetuating the cycle again.

Also, the payment system has to be changed as the cost of health care insurance is ratcheting up and is out of the financial reach of many people in this country. West Virginia is a little unique here. Our breakdown in terms of the uninsured is about 50 percent employed and 50 percent unemployed.

Again, the emphasis here must be placed on primary care. The Federal and State governments must use their collective financial resources to encourage primary care. I am confident that you are aware of the health status and the statistics on this country in comparison to the rest of the world and I do not need to relay these appalling statistics to you.

I do believe, however, that we can change our health status if the Federal Government takes a leadership role.

First, by reestablishing and redefining the concepts of the National Health Service Corp, primarily for family practice and general internal medicine, you can assist in alleviating major access problems in rural and underserved areas while again emphasizing primary care.

Two, by encouraging the States to establish under the Medicaid Program a "relative value scale," similar to Medicare and mandating that the States reimburse allied health professionals, which are more cost-effective also. You can encourage cost-effective care and efficient care and again, you can assist the underserved in rural areas while again emphasizing primary care.

Third, the Federal Government needs to provide the States with a lot more flexibility in the Medicaid Program and encourage the development of innovative programs for the uninsured and underinsured. Oregon, for example, has developed such a program but finds the Health Care Financing Administration to be a deterrent rather than an asset to reform.

Finally, drug manufacturers, and I know this from my clinic, need to be encouraged to donate medications to providers serving the uninsured with chronic ailments rather than to continue the restrictive circumstances that were established under the Dingell Act that was passed by Congress a couple years ago.

I want to thank you for the opportunity to share some of my ideas with you today.

[The prepared statement of Ms. White follows:]

GOOD MORNING, MY NAME IS PAT WHITE. I AM THE ADMINISTRATOR OF WEST VIRGINIA HEALTH RIGHT AND A THIRD-TERM MEMBER OF THE WEST VIRGINIA HOUSE OF DELEGATES. HEALTH RIGHT IS A FREE CLINIC SERVING INDIVIDUALS AND FAMILIES WHOSE INCOME FALLS BELOW THE FEDERAL PROVERTY LEVEL WITHOUT HEALTH INSURANCE OR MEDICAID COVERAGE. HEALTH RIGHT IS A FREE-STANDING PRIMARY CARE CLINIC PROVIDING DIAGNOSES, TREATMENT, LAB AND XRAY MEDICATIONS, AND REFERRAL SERVICES. ALL SERVICES PROVIDED AT AND THROUGH THE CLINIC ARE AT NO COST TO OUR PATIENT POPULATION. THE CLINIC'S ANNUAL OPERATING BUDGET IS LESS THAN $200,000 AND IT FUNCTIONS WITH A SMALL PAID STAFF WHICH INCLUDES A NURSE PRACTITIONER WHO PROVIDES THE MAJORITY OF PATIENT CARE UNDER ESTABLISHED MEDICAL PROTOCAL. IN ADDITION, THE CLINIC HAS A LARGE VOLUNTEER FORCE OF PHYSICIANS, NURSES, PHARMACISTS AND OFFICE PERSONNEL. HEALTH RIGHT IS A PRIVATE,

NON-PROFIT 501-C-3 CORPORATION WHICH IS STRONGLY SUPPORTED BY THIS COMMUNITY. THE THREE CHARLESTON AREA HOSPITALS PROVIDE SERVICES TO THE CLINIC AND THE PATIENTS WE SERVE. THE MEDICAL COMMUNITY PROVIDES A LARGE NUMBER OF VOLUNTEER AND PHYSICIAN SPECIALISTS WHO HAVE AGREED TO ACCEPT REFERRALS IN THEIR PRIVATE PRACTICES WITHOUT CHARGE TO THE PATIENT OR THE CLINIC. DRUG MANUFACTURERS' REPRESENTATIVES SUPPLY THE CLINIC WITH THE MAJORITY OF MEDICATIONS DISPENSED. LAST YEAR THE CLINIC GAVE AWAY MEDICATIONS VALUED AT OVER $2 MILLION SERVING 3,000 PATIENTS FOR OVER 10,000 CLINIC VISITS. HEALTH RIGHT FOLLOWS PATIENTS FOR CHRONIC AND SOME ACUTE CARE MEDICAL PROBLEMS. OUR PATIENTS DIAGNOSES ARE NO DIFFERENT THAN THE GENERAL POPULATION BUT ARE OFTEN MORE SERIOUS DUE TO A DELAY IN SEEKING MEDICAL CARE BECAUSE THEY DO NOT HAVE THE RESOURCES TO PAY FOR CARE. TODAY I HOPE

TO PROVIDE YOU WITH SOME INSIGHT INTO ACCESS PROBLEMS OF THE UNINSURED, THE BARRIERS THEY FACE AND RECOMMENDATIONS TO ADDRESS THESE BARRIERS. AS YOU ARE UNDOUBTEDLY AWARE, THERE IS A GROWING NUMBER OF INDIVIDUALS WITHOUT ACCESS TO HEALTH CARE SIMPLY BECAUSE THEY CANNOT AFFORD SUCH CARE. UNLIKE A DECADE AGO, OVER 90% OF THE MEDICAL DIAGNOSES TODAY ARE CHRONIC ILLNESSES AND YET THE MAJORITY OF OUR HEALTH CARE RESOURCES ARE CHANNELED INTO ACUTE CARE. ACUTE CARE FACILITIES ARE NEITHER DESIGNED, EQUPPED NOR STAFFED TO DEAL WITH CHRONIC ILLNESS. THE HEALTH CARE DELIVERY SYSTEM NEEDS TO REDIRECT ITS EMPHASIS TO DEAL WITH CHRONIC ILLNESS IN A PRIMARY CARE SETTING. THIS SHOULD INCLUDE PROVIDING MEDICATIONS TO TREAT CHRONIC DISEASES THEREBY DECREASING THE NEED FOR INPATIENT CARE. AS YOU ARE AWARE, HOSPITALS ARE THE MAJOR PROVIDERS OF CHARITY CARE. THIS IS NEITHER COST-EFFECTIVE,

MEDICALLY SOUND NOR GOOD HEALTH POLICY. HOWEVER, WHEN INDIVIDUALS CANNOT AFFORD PRIMARY OR CONTINUING MEDICAL CARE FOR CHRONIC CONDITIONS THEY WILL INEVITABLY END UP IN AN ACUTE CARE SETTING. THE INDIVIDUAL IS STABILIZED, THEN DISCHARGED ONLY TO FIND THEMSELVES AGAIN WITHOUT THE RESOURCES TO CONTROL THEIR CHRONIC DISEASES - AND THE CYCLE BEGINS ANEW. WITH CHRONIC ILLNESS, AN INDIVIDUAL'S HEALTH CONDITION DETERIORATES WITH EACH ROUND OF THE CYCLE. OUR PAYMENT SYSTEMS AT THE FEDERAL AND STATE LEVELS HAVE ENCOURAGED AND PERPETUATED THIS INEFFICIENT AND VERY COSTLY SYSTEM WITH COST-SHIFTING TO THIRD PARTY PAYERS. NOT TOO SURPRISING THE PRIVATE SECTOR HAS GOTTEN WISE TO THE COST SHIFT AND WITH FEDERAL ENCOURAGEMENT MORE LARGE COMPANIES ARE NOW ABLE TO PREVENT THE COST SHIFT THEREBY REDUCING THE NUMBER OF PAYERS SHARING THE COST OF CHARITY CARE WHICH DRIVES UP THEIR COSTS TO

PAY FOR OUR RAPIDLY GROWING NUMBER OF UNINSURED AND UNDERINSURED. THIS PAYMENT SYSTEM MUST ALSO BE CHANGED AS HEALTH CARE INSURANCE PLANS ARE OUT OF THE FINANCIAL REACH OF MANY IN THIS COUNTRY, AND ONLY PROJECTED TO RISE THROWING MORE PEOPLE INTO UNINSURED STATUS. AGAIN, EMPHASIS MUST BE PLACED ON PRIMARY CARE. THE FEDERAL AND STATE GOVERNMENTS MUST USE THEIR COLLECTIVE FINANCIAL RESOURCES TO ENCOURAGE PRIMARY CARE. I AM CONFIDENT THAT YOU ARE AWARE OF THE HEALTH STATUS OF THIS COUNTRY IN COMPARISON TO THE REST OF THE WORLD. I DON'T NEED TO RELAY THESE APPALLING STATISTICS. I DO BELIEVE WE CAN CHANGE OUR HEALTH STATUS IF THE FEDERAL GOVERNMENT TAKES A LEADERSHIP ROLE. FIRST, BY RE-ESTABLISHING AND RE-DESIGNING THE CONCEPTS OF THE NATIONAL HEALTH SERVICE CORPS FOR FAMILY PRACTICE AND GENERAL INTERNAL MEDICINE YOU CAN ASSIST IN ALLEVIATING MAJOR ACCESS PROBLEMS IN RURAL AND UNDERSERVED

AREAS WHILE EMPHASIZING PRIMARY CARE. TWO, BY ENCOURAGING STATES TO ESTABLISH A RELATIVE VALUE ~~SCHOOL~~ SCALE AND MANDATING REIMBURSEMENT TO ALLIED HEALTH PROFESSIONAL FOR THE MEDICAID PROGRAM. YOU CAN ENCOURAGE COST-EFFECTIVE AND EFFICIENT CARE AND ASSIST RURAL AND UNDERSERVED AREAS WHILE AGAIN EMPHASIZING PRIMARY CARE. IN ADDITION, THE FEDERAL GOVERNMENT NEEDS TO PROVIDE THE STATES WITH FLEXIBILITY IN THE MEDICAID PROGRAM AND ENCOURAGE THE DEVELOPMENT OF INNOVATIVE PROGRAMS FOR THE UNINSURED AND UNDERINSURED. OREGON, FOR EXAMPLE, HAS DEVELOPED SUCH A PROGRAM BUT FINDS HCFA TO BE A DETERRENT RATHER THAN AN ASSET TO REFORM. FINALLY, DRUG MANUFACTURERS SHOULD BE ENCOURAGED TO DONATE MEDICATIONS TO PROVIDERS SERVING THE UNINSURED WITH CHRONIC AILMENTS RATHER THAN TO CONTINUE THE RESTRICTIVE CIRCUMSTANCES ESTABLISHED BY THE DINGELL BILL.

THANK YOU FOR THE OPPORTUNITY TO SHARE WITH YOU MY PERSPECTIVE OF THE PROBLEM AND SOME RECOMMENDATIONS IN SOLVING THEM. I WILL RESPOND TO ANY QUESTIONS.

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Chairman ROCKEFELLER. Pat, thank you very much.

Earl Jarvis, I have known you for a long time and I am glad you are here this morning.

STATEMENT OF EARL JARVIS, DIRECTOR OF AGING PROGRAMS, PRIDE OF LOGAN COUNTY

Mr. JARVIS. Senator, thank you very much. I appreciate the opportunity to appear before this hearing, and it is good to see you, sir.

I would like to recognize on the printed list for today's hearing that my title lists me under innovative programs as a director of Aging Problems for PRIDE of Logan County, and I think sometimes in title 3 programs that is basically what we are involved in doing, is directing aging problems. A lot of times we find ourselves basically dealing with that. But you did announce it correctly when you said "programs."

As we look at long-term care and how it will be provided and financed in the future, we need to be constantly reminded that as new approaches are developed that we must also plan to shore up systems currently providing the majority of care in this country to the frail elderly.

Chief among those systems is that which is termed the informal caregiving network. All statistics indicate that 70 to 80 percent of the long-term care provided in this country is provided by the family and friends in the home. Without this network the health care cost of this country would soar most dramatically, to the point where we probably could not even calculate it.

It is imperative that all Government planners involved in long-term care be most cognizant that the provision of this care is both very stressful and intense in nature. Many times the frail elderly enter nursing homes and other institutional care because of the emotional and physical drain on the family members giving and providing that care.

All approaches to developing appropriate financial assistance for long-term care must give careful consideration to strengthening care given by this family caregiving informal network.

All financial approaches, whether they are through long-term care insurance or catastrophic health insurance or expanding the Medicare Title 19 Waiver Program of the Social Security Act or expanding, as I am suggesting, funding under title 3 of the Older Americans Act, must seriously address the appropriate funding for the provision of respite services, day care services, personal care services, and home delivered meals.

These services, among others, such as family caregiver support groups, can be implemented through the existing service networks if appropriately financed. It is important to note that some levels of these services are being provided. However, they are grossly underfunded and very sporadic.

There are statistics also that support the prediction that because of the demographics of the American aging society that the family caregiving network will diminish somewhat. However, all efforts must be made to support that network. Maintaining the frail elder-

ly in their homes is still the American choice for the American family.

Also among the systems that assist in keeping the elderly out of institutions is that system generally known as the aging service network under the Older Americans Act. This network delivers many services daily ranging from client finding and home delivered meals to the provision of personal care.

In the State of West Virginia alone this system, operating through the West Virginia Commission on Aging, currently serves over 50,000 of West Virginia's elderly annually at an annual cost of less than $125 per person.

This Nation cannot fiscally afford the consequences of the reduction of either of these particular services offered under the Older Americans Act, nor can it afford the reduction or the loss of either of these particular two systems providing long-term care in this country.

Generally speaking, the two systems, the family caregiving network and the Older Americans Act aging services network, are and should be somewhat integrated, perhaps more integrated than they currently are in the provision of long-term care services.

I currently direct a title 3 Older Americans Act funded project in Logan County. The work we do daily, in contact with the elderly and their families, is frequently frustrating because we do not have the funds necessary to employ sufficient numbers of staff to meet all of the needs. However, my years of experience in various positions in serving the elderly of this State lead me to recommend very strongly to this Commission that every approach be made to expand the funding of services in these two particular networks that are so important to this country.

Thank you, Senator.

[The prepared statement of Mr. Jarvis follows:]

PRESENTATION

TO

PEPPER COMMISSION HEARING

December 13, 1989
Charleston, West Virginia

As we look to long term care and how it will be provided and financed in the future, we need to be constantly reminded that, as new approaches are developed, we must also plan to shore up systems currently providing the majority of care to the frail elderly. Chief among those systems is that which is termed the "informal caregiving network". All statistics indicate that seventy to eighty percent of the long term care provided to the frail is given by family and friends in the home. Without this "network" health care cost would soar most dramatically. It is imperative that all government planners involved in long term care be most cognizant that the provision of this care is very stressful and intense in nature. Many times the frail elderly enter nursing homes and other institutional care because the emotional and physical drain from the provision of elderly care is too great for the family to continue to be involved.

All approaches to developing appropriate financial assistance for long term care must give careful consideration to strengthening care given by this "informal network".

All financial approaches, whether through long term care insurance, catastrophic illness insurance, expanding the waiver program of Title XIX of the Social Security Act, or expanding funding for services currently provided under the provisions of Title III of the Older Americans Act, must seriously address appropriate funding for the provision of respite services, daycare services, personal care services and home delivered meals. These services among others, such as family caregiver support groups, can be implemented through the existing service networks if appropriately financed. It is important to note the some levels of these services are being provided. However, they are grossly

under funded and are very sporadic.

There are statistics that also support the prediction that because of the demographics of the aging American family the "informal family caregiving network" will diminish somewhat. However, all efforts must be made to support the that network. Maintaining the frail elderly in their homes for as long as possible is still the predominant choice of the American family.

Also among the systems that assist in keeping elderly out of institutions is that system generally known as the "aging services network". This network delivers many services daily ranging from client finding and home delivered meals to the provision fo personal care. In the state of West Virginia alone this system operating through the West Virginia Commission on Aging currently serves over 50,000 of West Virginia's elderly annually at an annual cost of less then $125 per year per client. The nation cannot fiscally afford the consequences of the loss or reduction of either of these two systems in the provision of long term care. Generally speaking these two service systems, the "informal family caregiving" and the Older American Act " aging services network", are and should be somewhat integrated in the provision of long term care services.

I currently direct a Title III Older Americans Act funded project in Logan, County. The work we do daily in contact with the elderly and their families is frequently frustrating because we do not have the funds necessary to employ sufficient numbers of staff to meet the needs. However, my years of experience in various positions serving the elderly lead me to recommend strongly to this Commission that every approach to funding expansion of the services mentioned herein be pursued.

Respectfully submitted
Earl F. Jarvis, Project Director
Logan County Aging Program

Chairman ROCKEFELLER. Thank you very much.

Let me just ask one question, because we should have been concluded 30 minutes ago. I am told that there is more and more difficulty now in attracting doctors to rural areas.

I am told also that there are now only 100 OB/GYN's left in West Virginia and that as recently as 3 years ago there were more than 200, maybe 300. I know that the pediatrician who helped care for all four of Sharon's and my children, just said: "I've had it," left, got out of the profession. He was a wonderful doctor.

Are you seeing that? It is a leading question, but this obviously affects rural areas. Logan County has a fair number of doctors. Lincoln County, not many.

What are some thoughts that you might have on the supply, the adequacy of the number of physicians available or not in rural areas in this State?

Dr. WALKER. Senator, responding from Logan County since you mentioned it first, basically, I think we are not at the moment suffering as we were 10 years ago or 20 years ago for physicians being located in the county.

When you mentioned OB/GYN, however, we do have a drastic reduction in those, as do all areas of the country, because of the insurance problems, et cetera. I think that is basically what the OB/GYN's who are not practicing in our county have told me.

Beyond that point, however, I think we do have a drastic shortage——

Chairman ROCKEFELLER. You mean insurance related to malpractice?

Dr. WALKER. Yes. I do think we have basically a shortage of those dealing in geriatric medicine, terribly, in all of the rural areas of the country. We did have one geriatric specialist in Logan and he is no longer there.

Chairman ROCKEFELLER. Pat.

Ms. WHITE. I think that we need to basically change the—if it was up to me to make a decision on how this would be handled, I would change the whole health care delivery system, and then I would also change the method by which we recruit people into practicing medicine.

I am hopeful that the State of West Virginia is going to be dealing with some of those issues, and I think that the reimbursement system that has been established in the private sector and at the State level and under Medicare has encouraged physicians to specialize and has discouraged, through the reimbursement process, a physician practicing in rural areas.

That reimbursement system needs to be definitely changed, with a lot more emphasis on primary and general internal medicine, pediatrics, of course, OB/GYN, because we are in a crisis nationally on that.

Chairman ROCKEFELLER. Bob.

Dr. WALKER. We have got an enormous problem in human resources in rural West Virginia, rural America. Most small towns in rural areas cannot support a subspecialist. They can generally economically only support a generalist of some kind.

In West Virginia what we find is that of the people coming to medical school, half of them, on the one hand, leave the State,

three-fourths of them enter a subspecialty. So immediately, we are at a very low percentage.

Way over half of those remaining settle in one of the larger cities. This leaves us with just a woefully inadequate number of people who are willing to, able to, want to go to rural communities and practice.

You compound that with the fact that they are paid less, have fewer resources to work with, often have no emergency room, do not have a group to share call, and it really takes an enormously dedicated person to do that.

I think the other problem is that our medical schools are just unwittingly set up to educate people for suburban and urban practice. They are taught mainly by professors who have that orientation. I think we unconsciously discourage people. Without realizing, we discourage people who want to do rural practice. The system often does not understand those people.

So I think we have got to change a lot of things, and West Virginia is a great place to change them because we are predominantly a rural State. I think we need to encourage people in a lot of ways. We need to improve the working environment for rural physicians, make it a fair place to practice in terms of reimbursement, malpractice climate, and so on.

I think we need to change medical education so that it retains its quality but creates a sizable group of people who see rural practice as a challenge and feel uniquely qualified to do it. A heart surgeon is going to feel a letdown doing anything but heart surgery.

If we can educate people to be able to and want to do rural practice, I think they will do it because it is challenging, it is satisfactory, and I think that is going to take more than cosmetic change in medical education that I think is overdue, and I think West Virginia is poised to make some of those changes.

Chairman ROCKEFELLER. That is interesting. In the Medicare physician payment reform bill that was just passed by the Congress, we do not address medical education because we just cannot, but we did address reimbursement, as you know, and I think very substantially.

Of course, this new approach is going to phase in over a period of 5 years because there is quite a major change to take place. But I think our effort is going to genuinely improve the situation and remove some of the financial disincentives that steer medical graduates away from primary care.

In West Virginia for family-type primary care doctors, our bill will mean major increases in fees under Medicare. We are talking about possible fee increases of between 30 and 100 percent phased in over 5 years, with a 10-percent bonus on top of that for doctors practicing in underserved areas and I really think it is going to make a difference, at least I surely hope it will. That is the reason that I worked hard on the legislation.

I thank all of you extremely much. I regret again that we cannot do more questioning because the time is late and we have our final panel. Thank you very, very much for coming.

Panel 5 consists of Bea Burgess, past president of the Council of Senior West Virginians; Lee Beard, who represents the AFL-CIO; John Hurd, president of the West Virginia Chamber of Commerce;

and Kayetta Meadows of the West Virginia Education Association. We welcome you ladies and gentlemen.

Bea, I guess we will start with you since are first on the list. Bea Burgess.

STATEMENT OF BEA BURGESS, PAST PRESIDENT, COUNCIL OF SENIOR WEST VIRGINIANS

Ms. BURGESS. Thank you, Senator. Many people before me have done very, very well in talking about many of the things that I was going to talk about, so I am not going to share with you all of the information that I gathered about how rural we are and how to assist the elderly. You and the council have talked about this many, many times before.

I will say that long-term care is a personal problem with me now because my mother had Alzheimer's disease for 5 years, so I have experienced this and I am very, very concerned that our Nation address the problem. We cared for her at home.

You have in the paper that I have given to you the continuum of care. The Council of Senior West Virginians has always lifted up the needs of these lower levels of the continuum of care.

We have heard several of them talked about. I want to lift up two or three and one of them is chore service. You would be amazed at the number of older adults who could stay home months and perhaps even years longer if they had a little bit of help with some of the tasks at home.

Also one of the things that we have not heard here is transportation. You have heard that before from us. If the older adults do not have access to health services and groceries and the pharmacy their costs go up, as they have to be institutionalized. So transportation continues to be a critical component of what it takes for long-term care for the rural areas for older adults.

I have given to you a page on what we are paying now. We are paying $82 a month for chore service, average, in this State, neighbors going down the road and being paid a little bit to help some of their neighbors.

Senator Rockefeller, you know how many loving, kind people we have over these mountains and I think one of the finest programs we could have would be really to train them, as we have heard, and then give them enough so that they could go and help with these lower levels of care to their neighbors and keep them home.

We are paying $82, monthly, for adult family care home, and then we get up into an average of $120 a month for the licensed personal care home, and then when they have to go to the nursing homes, of course, at $1,600 a month.

On page 3, I have given you an update of the Medicaid expenditures for long-term care. We started about 15 years ago showing to our legislature that they could save money, as has been said here so beautifully before by some of the panelists. In 1967 fiscal year, we spent $12.5 million for long-term care and this past year we spent $113.7 million. You know, I added it up and that is $367 million over those years above the $12.5 million.

If we had redirected that money toward lower levels of care then, we would not be paying $113 million today. Just think, we are

$36.2 million behind in paying the bills for the nursing homes for Medicaid right now and the $367 million, would have helped control that greatly. We are supposed to be $80 million behind at the end of the year.

Just this past week I spoke about long-term care and a young woman came up at the end of the meeting and she said: "I run such and such a facility." She said: "I have two people that I would like to send home but I cannot, there are not the services there."

You take 153 institutions in this State and multiply them by two people and we are talking big money. Not only is it an unhappy situation for those people and their families because they are away from home, but the taxpayers are paying that. The Feds pay three-fourths of it but the State of West Virginia pays one-fourth.

We appreciate the Medicaid waiver in 19 counties and we appreciate your effort in helping to get it expanded.

Chairman ROCKEFELLER. Hopefully, at the end of next year it will be automatic for all counties.

Ms. BURGESS. We thank you for that.

Now, I would like to read some things that have not been covered so much.

Chairman ROCKEFELLER. You are going to have to be crisp.

Ms. BURGESS. I am going to be crisp.

Chairman ROCKEFELLER. All right.

Ms. BURGESS. In the last 20 years our health care system has disappeared and instead of it, we have an illness business. It does not have very much to do with the health of the people in America. Lobbyists for the health industries spent more on the Hill than gas and oil interests have.

Primary care, rural health care has been severely reduced, transportation, all of the social services that are supportive have been reduced.

Harvard and some other medical schools are now looking at research into basic nutrition and what happens in the chemistry of our body, and they are starting to find out things that I am amazed that the medical profession did not research many years ago. So we are starting to find out what can keep us healthy, and I think that is going to be cost-effective.

Fifteen years ago I found out about holistic health and there was not any doctor anywhere I could find that did holistic health services. But now I have found one, after suffering a major silent heart attack and getting all the diseases that older adults get.

So after being in his care for a couple of years, I am 20 years younger than I was 3 or 4 years ago and I really appreciate that and I wish it for every older adult in the Nation. It helps to stay healthy.

I have given your staff and the committee copies of two books to help them understand what chelation therapy is to help with heart disease.

As much as we spend on health care, we are not a healthy Nation. We are 19th, at the bottom of the barrel, in infant mortality, with South Africa. Our children are not as healthy as the children of any other nation in the western civilized nations and that is tragic, Senator Rockefeller.

We have talked about the people who have no access to health care, we have talked about private insurance. The politically disastrous catastrophic health bill was defeated not only because of the cost but mostly because the older adults thought long-term care was in there. That is the reason they supported it and when they found out it was not in there, they became hostile, which is too bad.

Many of the people in America are greatly distressed at the inequities in our taxing system. Why should Social Security contributions stop, level off, when your salary becomes $48,000? People do not understand this. Why do we have so many large corporations and thousands of wealthy people who pay no tax?

Every recent poll shows that Americans support increases in taxes for services they want, that are needed, that are fair, and that all of the people will benefit from. There would be great support for making a tax system fair and allowing all to make contributions for the betterment of the entire society.

Do you know that the steel industry pays more for health care than they do for the steel that goes in the cars? You know the industry is really suffering because of this.

We must have long-term care and we must have it for everybody, but we must have a healthy health system with a great emphasis on preventive health. Canada has led the way. Pittsburgh and Cincinnati and the State of Oregon have been doing regional health planning successfully for several years. So we have models that we can go to.

America must reaffirm that people are more important than profits. America must work to include each person in its concerns.

It is cost-effective to keep people healthy. It is cost-effective to see that all persons are healthy. It is cost-effective to have cooperation instead of competition. It is cost-effective to value people for themselves instead of abusing them for profit. It is cost-effective to have a coordinated health care system. It will be cost-effective to have national health care, including comprehensive long-term care. It is the only way we will have a healthy America.

Thank you very much. I am representing the various groups that made up our West Virginia campaign and also the National Council of Senior Citizens. We have been working on this for a long, long time, so it is a joy and a thrill for me to sit here and hear other people saying what we have said for so long. Thank you.

[The prepared statement of Ms. Burgess follows:]

THE PEPPER COMMISSION HEARING - Charleston, W. Va.
December 13, 1989

Senator Rockefeller, Members of the Commission and friends. I am Bea Burgess, of Nitro, West Virginia. As a member of the Council of Senior West Virginians and the National Council of Senior Citizens I have long been concerned with the health care services of our country, and the needs of the people which are not being addressed. I served for 15 years as a Church and Community Worker in Monroe and Fayette counties, both very rural and with a high percentage of older adults. It is a privilege to be here this morning to speak.

I wish to speak of Long Term care as a family problem. Families of this nation give 85% of the long term care, and 80% of the families of this nation have a person in the family needing long term care services. My family is one of these statistics. My mother died of Alzheimer's Disease, just a year ago. Our family cared for her with support from visiting nurses and several short hospital stays.

One-third of the families giving long term care live under the poverty level, and most of the care-givers are women. Many families use their resources and then mortage their home, or even use funds which were to be used to educate their young. The financial drain on a family is severe at best and disasterous at the worst.

One-half of the births in the nation are to women who are in poverty. The lack of pre-natal care to many gives us unhealthy babies whose cost is extremely high, for several years, some for life. Many children are born with defects - MS, CP, CF, and other developmental disabilities. Institutionalization is very costly for these children. Yet many times there are no services available to allow the families to keep the children at home.

For those under 44, trauma is the leading cause of death. For those under 34, trauma is the leading disabler, and it kills more persons than disease. Each year a million persons receive head injuries, 100,000 die and 60,000 - 90,000 are permanently disabled. Medicare and Medicaid do not pay for the services needed by the families. There is a Title XIX program which may possibly used. West Virginia has limited resources available, but none for the severely disabled. They must have a structured environment. Group homes would be most helpful to

the families struggling with this type of family care problem.

Although the elderly are a large group needing Long Term Care, you can see they are far from the only ones.

West Virginia follows Vermont in being the most rural state in the nation, with 187,902 (56.8%) of those living in the state and over 60 years of age living in rural areas./ Economic conditions have forced many younger persons out of the state, leaving older adults with fewer care-givers available, and many times living alone (82,793, 25% of the elderly).

We have 330,525 persons in West Virginia 60 years of age and over, with 27.4% of them being 75 years and over (90,570). Over 16% of the 60+ group live below the poverty level (55,613), 13,637 or 4.1% are minority persons, and 27,441 or 8.3% are socially needy.

Many of the persons in rural areas are widows of men who worked as timbermen or on a farm and were not on Social Security. Most are now on SSI, $388 per month for their total income.

You would be shocked at the number of older adults in the state who have had little or no health care in their life, many are still not on a lot of medication. When their health begins to fail, they need services which can help them stay at home and as healthy as possible. Chore service allows a neighbor to be reimbursed for cleaning the house, doing laundry, perhaps buying groceries or cooking a meal a day. They are paid by the task, and we average paying $82 a month per person for this assistance. Sometimes health services are needed. One time in Monroe County one home health nurse was keeping 37 patients at home who would have had to be in a nursing home without her services.

The community services needed are transportation to health, pharmacy and grocery services, and nutrition services./ If health deteriorates the first option beyond the home is adult family care, where a family take in one or two persons and care for them as they would their own relative.

You have the chart of the Continuum of Care, and an explanation of the costs of services in this lower level of care.

Personal Care homes move a person outside their community, generally, and they must be mobile. This makes continued contact with family and friends very difficult.

The Council of Senior West Virginians has lifted up to the legislature the opportunity to help older adults stay in their homes at far less cost to the state for about 15 years.

MEDICAID EXPENDITURES FOR LONG TERM CARE

Fiscal Year	Total Medicaid Eligible Persons	Total Certif. Nursing Home Beds	Total Medi-caid Beds	Medi-caid Beds as % of Beds	Medi-caid Patients as % of All Medi-caid Per-sons	Total Medicaid Expends. (Millions)	Long Term Care Expends. (Millions)	Long Term Care as % of Total Medi-caid Expends.
1976-77	145,766	3,906	2,314	59%	1.6%	$ 64.6	$ 12.5	19.4%
1979-80	152,000	5,349	3,740	70%	2.5%	$106.0	$ 26.8	25.3%
1982-83	174,353	7,329	5,123	69%	2.9%	$134.3	$ 48.2	35.9%
1985-86	224,000	8,291	6,000	72%	2.7%	$209.4	$ 69.8	33.3%
1986-87	241,000	9,502	6,795	72%	2.8%	$279.4	$ 82.5	29.5%
1987-88	299,881	10,415	7,200	69%	2.4%	$269.1	$101.3	36.2%
1988-89	325,375	10,901	7,400	68%	2.3%	$303.6	$113.7	37.5%
INCREASE 77-89 ($)	179,609	6,995	5,086	-	-	$239.0	$101.2	-
INCREASE 77-89 (%)	123%	179%	220%	15%	44%	370%	810%	93%

West Virginia is today $36.2 million in arrears in Medicaid payments, with the total to rise to more than $80 million by the end of the fiscal year. A rise of over $100 million in the last 12 years has gone to nursing homes, yet the funding level for the lower levels of care is practically the same as it was in 1977.

Many persons are inappropriately placed in nursing homes. They are there because in-home and community services are not available or are inadequate in their community, or they have too much income. Last week I spoke to a group on Long Term Care

and afterward a young woman who manages a nursing home said she had two who should be returned home but there were no services in their communities. If one home has two, think of how many we have in our 153 institutions, and the cost to the citizens which is unnecessary.

Older adults find that when they go to a nursing home, their resources saved for a time such as this vanish in three or four months. The cost is then paid by the Medicaid program, which is 76% federal, 24% West Virginia, for 70% of the cost.

West Virginia has a Medicaid waiver program in 19 counties of the state. This helps keep many persons at home and healthier and happier than they would be in a nursing home, and several can be cared for at the cost of one nursing home patient.

The national cost for nursing home care is $41.6 billion for the 1.6 million elderly who are there, and the families pay for half of this cost themselves.

One thing West Virginia has an abundance of - and that is caring people. The mountains are full of persons who would sacrifice to help their family and their neighbors. There is a great labor force, and the small sum they would be paid for their assistance would be welcome to many unemployed families. They do not have resources to travel to give assistance.

In the last 20 years our health care system has vanished. In its place is an illness business which has no concern for the health of the people of America. Services follow reimbursement policies. For several years the so-called health industry paid more on Capitol Hill than even the gas and oil interests. The results are that primary care and particularly rural care has been severely reduced, doctors eliminated in many areas, transportation services reduced. The entire emphasis is on patching a person up, rather than finding out what is wrong and making the body healthy again.

Harvard and several other medical schools have been doing research into the causes of the breakdown in various of our bodily systems, with a view to working to keep us healthy. Much has been discovered about the role of nutrition, and many in our nation are becoming truly health-conscious.

Fifteen years ago I learned about holistic health. I could find no doctor who was offering this type of health service. Now I have found one, and

5.

I am 20 years younger than I was three or four years ago. The chronic degenerative diseases which affect the elderly were coming on me very quickly. They are now quite well controlled, and I function better than I have in years.

A silent heart attack three years ago was a major one. Chelation therapy has been used to clean out my vascular system, and my health has been restored. The vitimin and mineral therapy has restored much of the health I had lost in several of my systems. I give to the committee the book The Scientific Basis of EDTA Chelation Therapy by Dr. Bruce Halstead, and also the recent protocol Protocol of the American College of Advancement in Medicine for the Safe and Effective Administration of EDTA Chelation Therapy. This Committee should become educated about a great new treatment. In some European countries chelation therapy is required before open-heart surgery is recommended.

Our illness business uses great amounts of high-tech equipment. The very highest and newest procedures are funded, and therefore, they are used.

Yet America is not a healthy nation. We spend over 10% of our GNP on health care and yet we are 19th in infant mortality, scoring near South Africa, and our children are not as healthy as children in any other industrialized nation. We have 18.6% of our people with no health insurance, and therefore no access to health services. That amounts to 37 million Americans.

Private insurance covers only 1.4% of the costs of long term care, most of the policies have pre-existing condition limitations and exclusions, and some require prior hospitalization, which is not the case of many persons needing long term care. Medicare covers only 2% of long term care costs. If we had a national insurance policy we still would have 6 million persons with no access to health care. Private insurance will never cover more than 20% of those in need.

The politically disasterous catastrophic health bill was defeated not only because of the cost but mostly because older adults wanted coverage for long term care, and they thought it was included.

The question becomes, how do we do this? How do we pay for this? We must have a health system instead of an illness business. We must educate for wellness. Primary care services must be available to all.

Expanding Medicaid is not the answer. It reaches only half of those in need, it is reduced quickly, it discriminates against the working poor who are just above the poverty level. The states have suffered great losses in revenue from the federal level in

revenue sharing and reductions in social and health services. They cannot pay for an expansion of services.

Many of the people in America are greatly distressed at the inequities in our taxing system. Why should Social Security contributions stop at $48,000 in income? Why do we have many large corporations and thousands of wealthy persons who pay no tax?

Every recent poll shows Americans support increases in taxes for services they want, that are needed, that are fair and that all will benefit from. There would be great support for making a tax system fair, and for allowing all to make contributions for the betterment of the entire society.

Rising health care costs for most companies is the single largest cost of doing business, e.g. for auto makers health care costs more than steel. Our nation is becoming crippled because of this bias in reimbursement which has given great rise to health costs. The added expense because of health problems of the drug abusers, and the costs to assist AIDS babies will finish bankrupting the illness business.

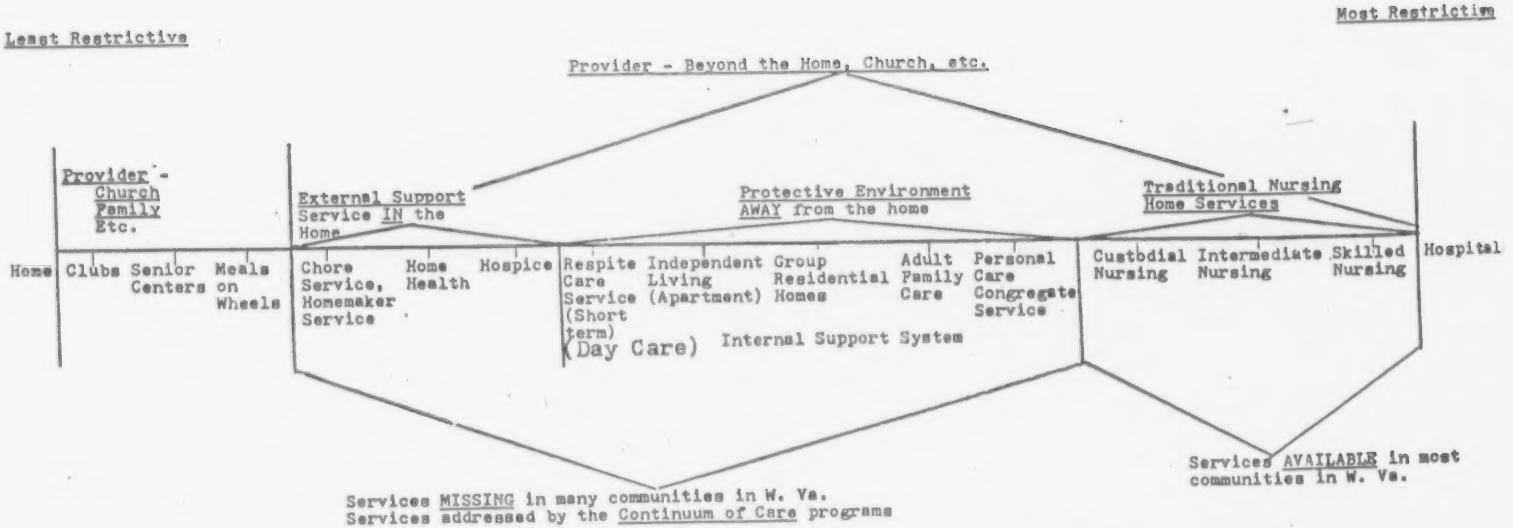
America must have Long Term Care for everyone. America must have a healthy health system, with a great emphasis on preventive health. Canada has led the way. Pittsburgh and Cincinatti have been douing regional health planning successfully for several years. The models are there.

America must reaffirm that people are more important than profits. America must work to include each person in it's concern.

It is cost effective to keep people healthy. It is cost effective to see that all persons are healthy. It is cost effective to have cooperation instead of competion. It is cost effective to value people for themselves instead of abusing them for profit. It is cost effective to have a coordinated health care system. It will be cost effective to have NATIONAL HEATH CARE including comprehensive Long Term Care. It's the only way we'll have a healthy America.

On behalf of the West Virginia Long Term Care Campaign, a coalition of over 20 groups representing seniors, unions, churchs, minorities, children, and the homeless, I thank you for this opportunity.

THE CONTINUUM OF CARE - A CONCEPT MAKING
AVAILABLE THE LEAST RESTRICTIVE SERVICES
FOR NEEDED CARE



WEST VIRIGNIA FINANCING FOR CONTINUUM OF CARE SERVICES - 1989

Service	Persons Served	Cost per month
Chore Service Work done in home by neighbors paid by task performed	5100	Max. $110 Average $82
Adult Family Care Home Person lives with a family in the community, two allowed in each home.	880	$335 - $405 Average $82 Person pays from own resources (SSI)
Residential Board and care This service is new and guidelines have not yet been finalized. It will allow 3-8 persons in each home and the home must be licensed.		
Licensed Personal Care Homes Must be licensed. Persons must be ambulatory (limited exceptions). Congregate care.	1900	$446 Persons pay from their own resources (SSI) Average $120.
Custodial Care	8,000	$1600 (76% federal)
Medicaid Waiver - 19 counties only Medicaid used for chore service, in-home health assistance	953	

Facilities	
ICF or SNF	2
ICF only	68
ICF/SNF	49
ICF/MR	34
Total	153

Wellness system important key to healthy state

By Beatrice Burgess

Several articles lately have described the problems West Virginia faces in health care. Most of the articles deal with financing acute care only, which is an illness system.

A health-care system is concerned with wellness — keeping people at the optimum level of health possible for their circumstances. It is integrated with an educational system that teaches what wellness is, and the various components of maintaining it, so people can make responsible decisions concerning their wellness. This wellness is also supported by several kinds of social and vocational services and transportation. Both in-home and community services must be available.

Under a wellness system, prenatal and infant clinics teach mothers health care of infants and family. The Women, Infants and Children program has been extremely effective in reducing infant mortality and in producing healthy babies. (In 1988 only 49 percent of the women and children in West Virginia who were eligible could obtain the services, because of less than adequate funding.) Education in the school system for health and wellness is supported by providing nutritious food along with the understanding of its importance.

Primary health care is emphasized, so that people have checkups with doctors and clinics to stay as healthy as possible. Community support is given to those with mental, emotional or developmental problems so that they can be helped to reach their maximum functioning level and make their contribution to society.

Environment is considered important and great effort is made to keep personal and community environment healthy and free from disease-producing elements. Citizens are involved in issues, and work to see that the government has their cooperation in reaching well-defined goals of health and wellness.

This is a dream? This is the West Virginia state health plan. The plan was developed during the early 1980s. What happened? Where is wellness? How did we get an illness business instead of a wellness system?

Services follow reimbursement policies. PL 93-641 of 1974 mandated a system of coordinated and comprehensive health planning for all health services. We did it.

But in the decade following, national medical, hospital and nursing home groups spent more on lobbying on Capitol Hill than even the gas and oil groups. Funding was made available through Medicare and other systems for the highest technologies for acute care. Wellness services were severely cut in funding, including rural health clinics, primary-care clinics, rural doctors and nurses, dental health, public health mental health and other social service support systems. Wellness was not a health concern. Education funding was cut, as were transportation services.

Suddenly health planners were hearing "competition" and "economy of scale." Each hospital wanted the latest technology available. The other elements of good health care were ignored.

The health care system was changed very quickly into an illness business.

There had been health planning prior to 1974 and some areas of the country continued to work cooperatively using the expanded planning system. Cincinnati and Pittsburgh were two to have area-wide planning for all levels of health care. The entire state of Oregon implemented a system focusing on primary health care with case management using nurses as the entry point of care.

Several countries, notably the Scandinavian ones and Canada, have built their health systems on wellness. They have kept their total health-care costs very low in comparison to us — and they are a healthy people, while we are not.

I served on the board of the West Virginia Health Systems Agency for several years. When providers of all types sit down with consumers representing all areas of the state and social and economic levels of society to do health planning, the results can be focused on the needs of people, and the results can be beautiful.

The first plan in 1980 dealt with health education, primary care, perinatal and family planning, acute care, heart disease, trial and occupational health, older adult and behavioral health. In 1982 a more complex state plan was issued and various components have been revised since then. Some elements of the planning system were retained, but funding for the planning was severely reduced and curtailed the vision of planning for health and wellness.

In 1982 all social and public health funds were cut 20 percent at the federal level. Since then state funding has followed federal funding with more going into acute care and nursing homes. Preventive health and wellness programs have been eliminated or sharply reduced.

In 1977 our state paid $12.5 million for Medicaid to nursing homes. In 1987 we paid $82.5 million. We pay 70 percent of the total cost of nursing homes in West Virginia because savings are eliminated in three or four months for most people who go to nursing home care.

The Council of Senior West Virginians has faithfully pointed out to the legislators for 15 years the need to increase in-home and community services as a way to cut the rise in nursing home costs. Today these in-home and community services are at almost the same funding levels as they were in 1977.

Many people could manage well at home for years with chore service to help with some tasks they can no longer perform, transportation to health, pharmacy and food services, home health and nutrition services. Many people can be served on this level for the cost of one nursing home patient.

Education for the medical profession has been negligent in emphasizing wellness. Research has been generally high in high-tech areas, leaving neglected the several schools of medicine, Harvard being one, are majoring in this field and are discovering the role of nutrition, environment and lifestyle in maintaining health.

Several countries, notably the Scandinavian ones and Canada, have built their health systems on wellness. They have kept their total health-care costs very low in comparison to us — and they are a healthy people, while we are not.

Canada has let each province develop its own health system, but it is a health system. Everyone has primary health care. If you become ill and need high-tech equipment you may have a long waiting period.

Congress set up a bipartisan Commission on Long Term Care with Claude Pepper as chairman. When Pepper died, Sen. Jay Rockefeller, D-W.Va., became chairman. People who believe in health care and understand the need for in-home and community services, as well as changes needed in the Medicare system, should write to Rockefeller at SH-724 Hart Office Building, Washington, D.C. 20510-4802.

It is cost-effective to keep people healthy. It is cost-effective to assure that all citizens have good health. It is cost-effective to have cooperation instead of competition. It is cost-effective to value people for themselves instead of abusing them for profit. It is cost-effective to have a coordinated health care system. I vote for and work for a truly healthy health-care system.

Burgess, now a resident of Nitro, formerly was a church and community worker in Fayette and Monroe counties and was vice president of the former West Virginia Health S[illegible]

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Sen. Jay Rockefeller
The Pepper Commission Hearing
Charleston, W. Va.,

Dear Sen. Rockefeller:

Enclosed please find a letter from a holistic health doctor who is a surgeon. This explains his questions about vascular treatments which led to his investigation of chelation therapy.

He has also included information on an update on scientific research which is presently being conducted by the FDA.

I hope this will be helpful to you in becoming more up-to-date on this new procedure.

Sincerely,

Bea. Burgess

Beatrice R. Burgess

STEVE M. ZEKAN, M.D.
1208 Kanawha Blvd., E.
Charleston, WV 25301

Telephone: 343-7559

December 12, 1989

Miss Beatrice Burgess
117 Lock Street
Nitro, WV 25143

Dear Bea:

I am not surprised about the response to your request concerning acceptance of chelation therapy. It has become almost more of a political (emotional) issue that a scientific one.

My initial introduction to the subject was also frought with marked skepticism and even (unfortunately) fear to show an interest in the subject.

Three things drove me to scientifically look further at it:

1. I had no experience with EDTA and had never seen any physician use it. This was in my own twelve years of medical experience.

2. In doing vascular surgery, I was and am still confronted with patients with nonoperable vascular disease, such as frequent leg and foot pain, who are in need of limb salvage techniques. Patients with other operative procedures were requiring re-operations after 3-4-7 years. We both were looking for ways to postpone or eliminate the extra procedures.

3. I had researched hyperparathyroidism and had given a resident research paper on it. The calcium removing or dropping effect of chelation had been postulated to me as removing calcium arterial plaque. However, I felt that possibly the EDTA effect could be due to the connective tissue breakdown (antifibrotic) induced by hyperparathyroidism. I contacted the national organization regarding any references to such a potential. This led to an invitation to attend the semiannual meeting of the now ACAM (American College of Advancement in Medicine).

Open-minded at this meeting and asking many questions of many competent physicians lead me to feel that maybe there was some validity to the use of EDTA in arteriosclerosis. I studied the accepted protocol of the American Board of Chelation Therapy.

My first patient was another surgeon in Charleston who was a diabetic. He was having constant foot and leg paresthesias. He had a four vessel coronary bypass and clinically did not look very good. He agreed to try the chelation after we discussed it at length. He trusted my medical judgment and knew of my interest in physiology.

Dr. MacDonald's feet burning left for six hours after his first treatment. After his second treatment, the burning left for 24 hours. Then after the third treatment, the pain was gone. His claudication improved remarkably after he received 30 treatments. He was very beneficial in referring a number of other patients and physicians. In fact, of the first ten people who received the treatment, three of them were doctors.

They have <u>all</u> recorded positive benefits from the prescribed treatment. I examined the creatinine clearance (renal function) of the first 20 patients treated, in fear of harming them, and found a 16% improvement on average of this function. The patients themselves were referring other patients. I certainly was not advertising this service. As one patient would get better, then new patients would come in and ask me about the treatment. Certainly, if the patients were dissatified with the results, they would not be referring their friends. I also would not jeopardize my reputation if I did not personally feel it was helping.

In fact, my time spent with chelation was taking me away from surgery and the net effect was an actual loss of money because of it. Ethically, I feel that patients need to be treated as I would want to be treated, and that included chelation.

The arguments against chelation as I see them are:

1. There is no literature to support it.

2. There are major organizations against it.

3. There are toxic side effects.

4. Insurance companies do not pay for it.

5. There is no double blind study using EDTA for arteriosclerosis.

I have enclosed several extensive reference books regarding EDTA. Many are books available at the Library of Congress, some I have.

Many of these studies demonstrate significant improvement in diseased organ systems. An article entitled "An Opinion, Chelation Therapy of Atherosclerosis" in December 1984, Drug Intelligence and Clinical Pharmacy shows an article biased against EDTA. If one reads the article and interprets the data, the conclusion certainly would be to raise a question of possible benefits for EDTA. However, the conclusion is coldly negative and obviously biased and non-objective.

Frequently, well thought of physicians are asked about their opinion regarding EDTA. It is unfortunate to see strong negative statements from people who have never given EDTA treatment, who do not even know what the standard dosage or number of treatments is and often don't know what EDTA stands for. Interestingly, some physicians (like myself) that are skeptical at first and start using EDTA, see its benefits and become advocates. Russ Jaffee, M.D., Ph.D, previously of the N.I.H. is an example of this.

There are many organizations who do not endorse EDTA chelation therapy. These decisions are often bureaucratic and committee generated as one or two individuals do not want to share responsibility for the statement. A domino effect of one elephant leading another has been created. With each person just accepting what the previous person has said regarding the data and not taking the effort and moderate time to thoroughly review it. Unfortunately, bad rumors can spread cancerously.

Several organizations assertively endorse the study and proper administration of EDTA. There is an American Board of Chelation Therapy (with a Candidate and Fellowship status), as well as the American College of Advancement of Medicine with its nearly 1,000 membership of physicians from around the world and their innovative thinking. There are also many Preventive Medicine Organizations that strongly approve and endorse chelation.

Insurance companies are run as businesses to make money. They are not personally responsible to the patient. They are only contractually responsible. If they can show any possible reason not to pay, they will seize it. It is not surprising to see no allowance for chelation when often times they are in the constant hassal to pay or allow for widely accepted surgical procedures endorced by Our Fellows of the American College of Surgeons.

Toxicity of EDTA is now essentially a non-issue. With periodic renal evaluation, checking for toxic metal exposure and with lower doses than were used in the 1950's and early 60's, EDTA has been rendered minimally hazardous. Its low allergic potential is seen by its use in myriad food products.

Finally, I see the double blind, placebo controlled, study regarding EDTA in arterosclerosis as a breath of fresh air. Because of the loss of patent rights of EDTA, no drug company has been willing to support a multi-million dollar study of this compound simply to add another indication for its use, when the drug is already available and legally can be used by a licensed physician after informed consent by his patient. We members of ACAM have financially gathered together along with several major philanthropic groups (generally from organizational heads benefited as patients from EDTA chelation) to fund the study. The study is at Walter Reed Army Hospital as well as Letterman Hospital in San Francisco. In a recent newsletter bulletin from the FDA, its advisory board was critical of the use of EDTA chelation therapy. These advisors had theoretically researched the subject thoroughly. However, they were not aware of the FDA approved study presently being conducted at the reputable Army Institution. It has been an embarrassment to the FDA and is infact, illegal. The publicizing of biassing or prejudicial reports cannot be done when an IND (investigating new drug) is under FDA study. I understand from Dr. Ross Gordon (the holder of the IND for EDTA) to expect a retraction statement in the FDA Bulletin in the Febuary '90 issue.

The physician responsible for the study is:

Raymon J. Lipicky, M.D., Ph.D
Chief of Cardio-renal Division of FDA
301-443-0319

Simply, the application and approval of the FDA study has fostered interest in EDTA chelation. Younger and more physicians are registering for the courses on chelation and attending the national meetings.

I feel these events signal the advent of a new exploration of chelation and chelating agents; and more importantly, a much needed preventive medicine modality, that is cost effective and will help our country and the world "rectangularize" the death curve. That is to have a good quality life style to a point in late life when high tech and expensive modalities are not indicated or wanted by the patient, his doctor or their country.

I hope my thoughts on this are helpful.

Sincerely,

Steve Zekan, M.D.

SZ/jm

Enclosure

AN OPINION

CHELATION THERAPY OF ATHEROSCLEROSIS

Kaye L. Rathmann and Larry K. Golightly

ABSTRACT: Chelation therapy with intravenous injections of edetate disodium is being promoted to the public as a nonsurgical means to treat coronary or other arterial atherosclerosis. The rationale for use, clinical efficacy, and safety are reviewed. Acceptable evidence supporting chelation therapy for atherosclerotic vascular disease is lacking.

Drug Intell Clin Pharm 1984;*18*:1000-3.

KEY WORDS: edetate, chelation therapy, atherosclerosis.

CHELATION THERAPY has been popularized through various media. Repeated intravenous injections of edetic acid (EDTA; ethylenediamine tetraacetic acid) or its salt (edetate disodium) are being promoted widely to the public as a nonsurgical means to alleviate symptoms and correct the underlying disorder in a number of conditions associated with atherosclerotic vascular disease. It is estimated that ~0.5 million individuals with these conditions are treated with chelation each year in the U.S. (Personal communication, R. Gordon, President, American Academy of Medical Preventics, 1 December 1983).

The American Academy of Medical Preventics (AAMP), the foremost proponent of chelation therapy, suggests that patients with atherosclerotic disease complete a medical history questionnaire, have a hair sample analyzed for trace mineral composition, and undergo a series of 30 to 50 infusions of edetate disodium in doses of ~3 g each. Two to four infusions are given per week at a cost of $60 to $100 per infusion. Oral vitamin/trace mineral supplements usually are provided. The AAMP recommends follow-up treatment every 3 to 12 months.[1]

KAYE L. RATHMANN, B.S.Pharm., is Clinical Pharmacist, Rocky Mountain Drug Consultation Center; LARRY K. GOLIGHTLY, Pharm.D., is Associate Director, Rocky Mountain Drug Consultation Center, 645 Bannock St., Denver General Hospital, Denver, CO 80204.

Rationale

Edetic acid is a compound that forms stable, soluble complexes with divalent and trivalent cations. Unlike parenteral edetate calcium disodium, which does not affect serum calcium levels significantly, edetate disodium primarily complexes calcium and can rapidly decrease serum calcium concentrations.

Edetate disodium originally was administered to patients with coronary artery disease and angina during the 1950s. Its use was based on the idea that chelation therapy would lower serum calcium, decalcify metastatic calcium deposits and atherosclerotic plaques, and thereby perform a "chemical endarterectomy."[2] Proponents have suggested that edetate disodium also may attack directly and dissolve calcified vascular plaques,[3] produce sustained depression in plasma cholesterol levels,[4-6] restore certain mineral-enzyme balances essential for repair of atherosclerotic vascular injury,[4] and act as a calcium-channel blocker with actions analogous to several of the newer antianginal drugs.[7] Further, it has been hypothesized that chelation may benefit some forms of dementia by lowering total body stores of aluminum.[8]

Several lines of evidence from pathological studies suggest that the above rationale for the use of chelation therapy for atherosclerosis is suspect. Vessel injury and smooth-muscle cell proliferation are probably the initiating events in atherogenesis.[9] The most characteristic lesion of advanced atherosclerosis consists principally of a lipid-rich center, primarily cholesterol and its esters, surrounded by lipoproteins, collagen, proteoglycans, and elastic fibers. These components are intermixed with fibrin that encapsulates the lesion. The fibrous plaques may become altered further as a result of hemorrhage, intramural thrombosis, and eventually calcification.[10] Calcium deposition occurs, as in several other pathological processes, following cell injury and death. Thus, while calcium is often a prominent part of complicated or advanced atherosclerotic lesions, it is doubtful if it

is a primary factor in the pathogenesis of the disease.[9,11] Agents that affect serum calcium would, therefore, not be expected to influence the initiation or development of atherosclerosis.

Edetate disodium chelates ionized calcium. While it promptly removes ionized calcium from serum, it probably is incapable of directly attacking the elemental calcium that is bound to lipids and proteins in plaques. To date, there is no convincing evidence to suggest that edetate disodium has the ability to cause regression of atherosclerotic lesions subsequent to lowering serum calcium concentration.

Clinical Effects

A number of clinical investigators have described the use of chelation therapy for atherosclerotic vascular disease (Table 1). Most of the trials were conducted two to three decades ago and, as shown in Table 1, many lacked the required research methodologies and elements to assess objectively treatment efficacy.[17] Most patient series contained small numbers of subjects, diagnostic and evaluative criteria were largely subjective, controls were generally not used, effects of other concurrent medications or treatments were not described, and follow-up periods were typically short. In addition to the trials published in medical journals, at least two series of case reports have been compiled in book form.[18,19] These reports are also from uncontrolled trials and are, therefore, anecdotal in nature.

CORONARY ARTERY DISEASE

Most of the available reports describe striking benefit in the majority of patients treated and include case descriptions of relatively dramatic symptomatic improvement, particularly in individuals with angina pectoris. Frequency and, in some cases severity, of anginal episodes, as assessed by patients themselves, were lessened. Several document improvement or normalization of electrocardiograms after a number of edetate disodium infusions.

Table 1. Use of Edetic Acid and Edetate Disodium in Atherosclerotic Vascular Disease

PATIENTS (n)	AGE (yr)	DIAGNOSIS	STRICT ELIGIBILITY/ EVALUATION CRITERIA	RANDOMIZED	PATIENT/ EVALUATOR BLINDING	OBJECTIVE ASSESSMENT OF EFFICACY	STATISTICAL ANALYSIS	COMMENT	REF.
3	59-70	CAD, PVD	—	—	—	—	—	symptoms of coronary insufficiency and dementia markedly improved; prostatic enlargement eliminated	2
22	not stated	angina, PVD, nephrocalcinosis	—	—	—	—	—	peptic ulcers and hearing improved, "unusual" symptomatic relief of angina	3
15	44-76	diabetes mellitus, PVD, dementia, retinopathy, arthritis	—	—	—	—	—	peripheral vascular insufficiency improved, insulin requirements decreased	5
18	48-72	CAD	—	—	—	—	—	complete subsidence of angina in all but 2, technetium-99m ejection fraction increased 6%	7
20	46-73	angina, CAD	—	—	—	—	—	symptomatic improvement of angina in 19 of 20, exercise capacity increased	12
10	not stated	angina, CAD	—	—	—	—	—	symptomatic improvement of angina in 9 of 10 patients	13
81	not stated	CAD	—	—	—	—	—	"2000 consecutive infusions. . .no serious side effects or toxicity"	14
248	53-76	angina, CAD, hypertension, PVD	—	—	—	—	—	"pain syndrome completely disappeared . . .noise in the ears disappeared. . .arterial pressure was normalized"	15
9	not stated	angina, CAD	—	+	+	+	—	2 of 9 patients considered improved after 20 infusions	16

CAD = coronary artery disease, PVD = peripheral vascular disease

In one of the few trials in which long-term patient follow-up is reported, Kitchell et al. described their experience with chelation therapy in an open study of 38 patients with severe angina. Twenty infusions of edetate disodium 3-4 g were administered over a four- to eight-week period. Although no immediate effect was apparent, two-thirds of these patients exhibited a reduction in the occurrence of anginal episodes after treatment (based on their own impressions and measured exercise tolerance), and 40 percent showed electrocardiographic improvement usually beginning 6 to 12 weeks after edetate disodium infusions were discontinued. At the end of an 18-month observation period, 12 (32 percent) of the subjects had died from their original disease and only 40 percent maintained some subjective evidence of benefit. Based on these results and the outcome of a small placebo-controlled study that demonstrated positive effects in just two of nine angina patients, the authors concluded that chelation therapy did not provide lasting benefit and was not clinically useful to treat coronary artery disease.[16]

In an investigation of 18 patients with angina pectoris associated with coronary artery disease, symptomatology and left ventricular ejection fraction (using cardiac nuclear scintigraphy with technetium-99m) was documented both before and after 20 infusions of edetate disodium 3 g.[7] All patients improved clinically, and in all but two there was complete cessation of angina during chelation therapy. Ejection fraction increased from a mean of 60 percent to 66 percent (range of change, −2 percent to +16 percent), although it is unclear whether this was related to improvement of anginal symptoms. No patient was documented as having heart failure either before or after the trial. The overall increase in ejection fraction reportedly was statistically significant, but the method of statistical analysis was open to doubt.[7]

The above study is the only investigation of which we are aware that evaluated patients with objective measures of drug effect.[7] However, the relevance of these findings is unclear in the population studied. Other reproducible, prospective investigations in patients with angina have not been performed. Studies evaluating changes in exercise tolerance, frequency and severity of anginal episodes, nitroglycerin consumption, oxygen consumption, or double-product (heart rate × blood pressure) apparently have not been done. No prospective trials have yet compared chelation therapy with standard medical or surgical treatments for angina pectoris. The AAMP plans to undertake such studies, but until these results are available the relative efficacy of chelation therapy for coronary artery disease will remain questionable.

CEREBROVASCULAR DISEASE

As in coronary artery disease, several of the early reports of edetate disodium use for atherosclerosis described improvement in senility (dementia), depression, impaired speech patterns, muscular coordination, and other problems associated with cerebrovascular disease,[2,3] as well as resolution of intermittent claudication.[4] One trial reported clinical improvement (symptoms or means of assessment not described) in each of 15 patients given 20 infusions of edetate disodium for brain disorders.[8] Technetium-99m injections with subsequent scintillation camera measurement of counts of radioactivity on each side of the head were used as an assessment of cerebral blood flow. This technique, which according to the investigator had not been used (or validated) in any previous laboratory or clinical study, disclosed a reportedly statistically significant increase in cerebral blood flow. However, there are over 50 different etiologies of dementia. Fewer than 10 to 15 percent of patients are demented secondary to atherosclerotic disease.[20,21] These data, in combination with the lack of adequate description of brain disorders, suggest the value of these results is of doubtful clinical importance in the majority of patients.

Similarly, another trial in 57 patients used oculocerebrovasculometric analysis, ophthalmic arterial pressure vs. brachial blood pressure, to measure cerebral arterial occlusion. Fifty patients (88 percent) improved clinically (criteria not stated) and cerebral arterial stenosis, as measured by these methods, was reduced from a mean of 28 percent to 10 percent after 10 to 46 infusions of edetate disodium.[22]

In the absence of well-controlled investigations, the effectiveness of edetate disodium for cerebrovascular disease cannot be evaluated.

PERIPHERAL VASCULAR DISEASE

Several patient series included brief descriptions of symptomatic improvement in patients with peripheral vascular disease.[2,3,5,15] The most recent trial included four patients with advanced peripheral vascular insufficiency. Each patient had an infected foot lesion that exhibited poor healing; amputation had been advised in each case. Patients were treated with intravenous or topical antibiotics, debridement, hyperbaric oxygen in two cases, and repeated edetate disodium infusions. Lesions healed in each case over several months, and amputation of three toes was required in only one of the four patients. Edetate disodium was considered "the most important therapeutic factor in reversing the natural course of their disease," despite the multi-modal approach to these patients' care.[23]

Considered in total, studies of edetate sodium in atherosclerotic vascular disease have been uncontrolled, with assessment criteria absent or vague; adequate documentation of a specific diagnosis is lacking in most. Beneficial effects generally are not immediate and it is difficult to rule out a possible placebo response. There are no prospective, controlled studies comparing chelation therapy with standard medical treatments and no evidence to suggest an alteration in mortality associated with occlusive vascular disorders.

Adverse Effects

Edetate disodium is not a benign drug and has been associated with some adverse effects. Biochemical evidence (doubling of baseline serum creatinine) of transient nephrotoxicity occurred in 13 percent and acute oliguric renal failure developed in another three percent of 130 children in New York City treated with chelation therapy for asymptomatic lead poisoning. These children received dimercaprol (BAL) in addition to ede-

tate calcium disodium.[24] Nephrotoxicity is not a recognized complication of BAL, but it is a potential hazard with both edetate disodium and calcium disodium. Renal tubular vacuolization and hydropic degeneration have been reported on autopsy of two patients receiving one or more large doses (6-13.5 g over ~60 minutes) of edetate disodium for hypercalcemia.[25] Similarly, autopsy revealed vascular engorgement of reticuloendothelial tubular cells with eosinophilic granules and hemorrhagic manifestations in each of two patients with hypercalcemia treated with two to seven daily doses of edetate disodium 2-6 g.[26] Similar renal lesions also have been produced in edetic acid-treated animals.[27] A recent lawsuit awarded $550000 to a 51-year-old patient who developed progressive glomerulonephritis, ultimately lost function of both kidneys, and became totally dependent on dialysis after a series of edetate disodium infusions given over a six-week period.[28] One common reference (AMA Drug Evaluations) suggests that the nephrotoxic potential of this agent limits its usefulness to dire emergencies when death from hypercalcemic crisis is judged to be imminent.[29]

In addition to renal disorders, other problems have been reported with edetate disodium. Infusions given over less than three to four hours may potentially result in acute hypocalcemia, tetany, and cardiac arrhythmias. Other less common adverse effects include pain at the injection site, vasculitis, hypotension, hypoglycemia, and prolongation of prothrombin time.[14,29-31]

Place in Therapy

Opinion on the value of chelation therapy is divided. While advocates argue strongly in favor of edetic acid, a recent statement from the American Medical Association provides the following assessment:[32]

> The Department of Health and Human Services released a report entitled EDTA Chelation Therapy for Atherosclerosis in 1981 (HRST Assessment Report Series, Vol. 1, No. 18). It noted that chelation for this indication is controversial, that there is no accepted rationale for its effectiveness, and that its safety is questioned. The *Medical Letter* reviewed the experience over 20 years and concluded that there is no acceptable evidence that chelation therapy with EDTA is effective in the treatment of atherosclerosis and the adverse effects of the drug can be lethal.[33] The American Heart Association has also reviewed the data and found no scientific evidence to support the claims of benefit in patients with atherosclerosis. This opinion is shared by the American College of Physicians, The American Academy of Family Physicians, The American Society for Clinical Pharmacology and Therapeutics, the American College of Cardiology, and the American Osteopathic Association. In summary, there is general agreement that chelation therapy has not been established as an acceptable treatment for coronary or other arterial atherosclerosis.

Summary

There is consensus that chelation therapy has not been established as an acceptable therapy for coronary or other arterial atherosclerosis and has serious toxicities. ☆

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Chairman ROCKEFELLER. On that point, let me just say for the record that there were a lot of people who wanted to testify in addition to those who are testifying today. The reason that we just had to say no is now self-evident, in that we are 1 hour over our time. We just had to cut the witness list off at a certain point. But to those who wanted to testify but could not testify, I apologize. You are welcome to submit testimony and be in touch with us about your concerns.

Lee Beard.

STATEMENT OF LEE BEARD, REPRESENTING AFL–CIO, WEST VIRGINIA LABOR FEDERATION

Mr. BEARD. Thank you, Senator. My name is Lee Beard and I am here today as a substitute for Joseph W. Powell, who is president of the 70,000 members of the West Virginia AFL–CIO. Mr. Powell asked me to express his regrets at his not being able to be here in person, Senator.

Chairman ROCKEFELLER. I saw Joe's son last night and, in fact, Joe's son is a physician.

Mr. BEARD. Yes, he is.

Senator, the sad state of our Nation's health care is self-evident. Despite the $2 billion spent every day on health care and the fact that the United States spends 31 percent more of our resources on health care than does Canada, 65 percent more than Japan, 79 percent more than England, there are literally millions of Americans who have limited or no access to health care in the United States, the world's richest Nation.

In fact, as noted, 37 million Americans have no health protection whatsoever, a sobering fact. Three-fourths of those 37 million people are workers and their families, one-third are children. Additionally, as many as 50 million Americans have inadequate insurance coverage.

The West Virginia AFL–CIO is vitally concerned about the prospects for the future of all citizens as our health care system progressively and insidiously eliminates those at the lower end of our economic scale from health protections.

The sad fact is that although our Nation now has 5.1 percent unemployment, that is as of September, West Virginia had 8.1 percent, according to the Department of Labor's Bureau of Labor Statistics, the highest in the Nation, again.

Unemployed workers can rarely afford health insurance and because of the shift in our economy from production to service, millions of good jobs that provided health care insurance coverage disappeared, especially since the end of the Carter administration. These good jobs have been replaced by low-paying jobs that offer no benefits, not even health care.

It is instructive to note that of all the industrial nations of the world, only two tie health care to employment. One is the Republic of South Africa, the other is the United States of America. We are lagging behind the rest of the world, Senator, and it is high time that some major health care reforms are initiated in this country, and 89 percent of all Americans polled agree.

In this effort, the AFL–CIO has identified some specific areas of concern. First, costs must be controlled. Within recent years, the cost of health care has been climbing at a rate of double the rise in the average cost of living. This upward spiral must be arrested and turned around.

Senator, your amendment to the budget reconciliation bill this year to establish some maximum rates that can be charged by physicians under Government health programs promises to return some sense of responsibility to controlling health care costs in this country. However, much more needs to be done.

The fact is that many employers who still offer health care insurance for their workers are cutting back on provided coverage. They are increasing deductibles and shifting premium cost onto the workers, thus reducing the amount of their take-home pay and lowering their living standard.

Just in this morning's Gazette, Senator, you may have seen the story about what is happening with Union Carbide regarding the cost of premium insurance being shuffled over onto the workers.

Where employers continue to pay the total cost of premiums, the amount of money available for wage increases, innovations, equipment modernization is subsequently decreased. However, many employers no longer offer any health insurance to employees.

Private hospitals commonly engage in what has come to be known as patient dumping, where indigent patients are routinely transferred to public hospitals, sometimes at the risk of a patient's life, just because these hapless people have no insurance and cannot pay.

Over 11 percent of the gross national product of the United States is spent on an inadequate system of health care that ignores the plight of many of the poor and poverty stricken. By comparison, Canada, our neighbor to the north, provides health care for every citizen, while spending only 8.5 percent of their gross national product.

Our costs of health care have doubled just since 1980 to an astonishing $500 billion.

Chairman ROCKEFELLER. Actually, it is more than that.

Mr. BEARD. Access to health care must be made available to every person who needs it. Treatment of an illness or a condition suffered by any American should not be dependent upon an ability to pay but upon the need for the service. The rationing of health care only to those who can afford it is not only callous, it is barbaric and it violates the very principles upon which the medical profession was established, the Hippocratic Oath.

In addition to the kinds of hands-on medical care that commonly springs to mind, there are millions of others who need constant care but primarily of a custodial nature, not a medical nature. For example, there are over 2 million people in the United States with a diagnosis of Alzheimer's disease. At the present time, there is no cure or treatment for Alzheimer's. Savings that are gathered over a lifetime dollar-by-dollar are swiftly devoured, thousand-by-thousand.

Good custodial care in West Virginia commonly costs from $20,000 to $25,000 or more a year, every year, year after year. That cost represents more than what 50 percent of West Virginians earn

in a year. Smaller family size today means fewer relatives to share in this burden.

Alzheimer's patients have been known to live for a decade or longer, as have some victims of coma. For families of these patients there is no hope, no hope at all, ever.

Congress needs to develop a system that will provide needed long-term care without making a family so destitute that it must become an additional public burden on welfare. It is a national disgrace that only those who are rich or have good jobs can afford medical treatment, while those who often need it most, like people suffering malnutrition, who are more susceptible to disease, and the elderly, for example, are the very ones who are least apt to have access to medical treatment. Thus, is our national shame paraded before the world.

Thank you, Senator.

[The prepared statement of Mr. Beard follows:]

AFL-CIO Testimony by Lee Beard before the Pepper Commission
Charleston Area Medical Center, WVU Building
Wednesday, December 13, 1989

Good afternoon. My name is Lee Beard, and I am here today as a substitute for Joseph W. Powell, president of the 70,000-member West Virginia AFL-CIO. Mr. Powell asked me to express his regrets at not being able to testify here today in person, but a prior commitment made that impossible.

The sad state of our nation's health care system is self-evident. Despite the $2 billion spent every DAY on health care and the fact that the United States spends 31 percent more of our resources on health care than does Canada, 65 percent more than Japan, and 79 percent more than England, there are literally millions of Americans who have limited or no access to health care in the United States, the world's richest nation.

In fact, 37 million Americans have no health protection whatsoever, a sobering fact. Three-fourths of those 37 million people are workers and their families, and one-third are children. Additionally, as many as 50 million Americans have inadequate insurance coverage.

The West Virginia AFL-CIO is vitally concerned about the prospects for the future of all citizens as our health care system progressively and insideously eliminates those at the lower end of our economic scale from health protections. The sad fact is that although our nation now

has 5.1 percent unemployment, West Virginia has 8.1 percent, according to the Department of Labor's Bureau of Labor Statistics...the highest in the nation...again.

Unemployed workers can rarely afford health insurance. And because of the shift in our economy from production to service, millions of good jobs that provided health care insurance coverage disappeared, especially since the end of the Carter Administration. These good jobs have been replaced by low-paying jobs that offer no benefits...not even health care.

It is instructive to note that of all the industrial nations of the world, only two tie health care to employment. One is the Republic of South Africa. The other is the United States of America. We are lagging behind the rest of the world, and it is high time that some major health care reforms are initiated in this country, and 89 percent of all Americans polled agree. In this effort, the AFL-CIO has identified some specific areas of concern:

COSTS MUST BE CONTROLLED!! Within recent years, the cost of health care has been climbing at a rate of double the rise in the average cost of living! This upward spiral must be arrested and turned around. Senator, your amendment to the Budget Reconciliation Bill this year to establish some maximum rates that can be charged by physicians under government health programs promises to return some sense of responsibility to controlling health care

costs in this country. However, much more needs to be done.

The fact is that many employers who still offer health care insurance for their workers are cutting back on provided coverage, increasing deductibles, and shifting premium costs onto the workers, thus reducing the amount of their take-home pay and lowering their living standard. Where employers continue to pay the total cost of premiums, the amount of money available for wage increases, innovations, and equipment modernization is subsequently decreased. However, many employers no longer offer any health insurance to employees. Private hospitals commonly engage in what has come to be known as "patient dumping" where indigent patients are routinely transferred to public hospitals, sometimes at the risk of a patient's life, just because these hapless people have no insurance and cannot pay.

Over 11 percent of the gross national product of the United States is spent on an inadequate system of health care that ignores the plight of the poor and poverty-stricken. By comparison, Canada -- our neighbor to the north -- provides health care for every citizen while spending only 8.5 percent of the GNP. Our costs of health care have doubled just since 1980 to an astonishing $500 billion!

ACCESS TO HEALTH CARE MUST BE MADE AVAILABLE TO EVERY PERSON WHO NEEDS IT!! Treatment of an illness or condition suffered by any American should not be dependent upon an ability to pay, but upon the need for the service. The

rationing of health care only to those who can afford it is not only callous: it is barbaric and it violates the very principles upon which the medical profession was established...the Hippocratic Oath.

In addition to the kinds of hands-on medical care that commonly springs to mind, there are millions of others who need constant care, but primarily of a custodial nature, not a medical nature. For example, there are over two million people in the United States with a diagnosis of Alzheimer's Disease. At the present time there is no cure or treatment for Alzheimer's. Savings that are gathered over a lifetime, dollar by dollar, are swiftly devoured, thousand by thousand. Good custodial care in West Virginia commonly costs from $20,000 to $25,000 or more a year...every year...year after year. That cost represents more than what 50 percent of West Virginians earn in a year. Smaller family size today means fewer relatives to share in this burden. Alzheimer's patients have been known to live for a decade or longer, as have some victims of coma. For families of these patients, there is no hope...no hope at all...ever.

Congress needs to develop a system that will provide needed long-term care without making a family so destitute it must become an additional public burden on welfare. It is a national disgrace that only those who are rich or have good jobs can afford medical treatment...while those who often need it most, like people suffering malnutrition who

are more susceptible to disease and the elderly, for example, are the very ones who are least apt to have access to medical treatment. Thus is our national shame paraded before the world.

Thank you.

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Chairman ROCKEFELLER. Thank you, Mr. Beard. John Hurd.

STATEMENT OF JOHN HURD, PRESIDENT, WEST VIRGINIA CHAMBER OF COMMERCE

Mr. HURD. Thank you, Senator. Like Lee Beard, I am here as a substitute for the volunteer leader of the West Virginia Chamber of Commerce, Michael Perry, from Huntington, who had other long-term commitments. My name is John Hurd and I am the president of the State chamber.

As time allowed us, after being notified of the hearing, we surveyed several of the small business members of the State chamber and asked them to comment specifically about health care as it relates to small business to determine their experience with health care costs in recent years.

We are convinced that employers at that level are making a valiant effort to provide or to continue a reasonable health insurance plan for their employees. Our small survey involved a manufacturer, a heavy equipment sales and service company, a lumber and building supply company, and a department store.

We asked them to track their health care experience over a 5-year period and we have prepared a brief account of the experience of each company and that is attached to my official statement.

There appears to be, however, without going into each one of those surveyed, a common thread of action that the collective group has taken to provide insurance in the face of rising costs. Those actions included, one, a frequent shopping for different carriers, becoming self-insured was another step they took, especially when large rate increases in cost appeared to be eminent.

Several employers spoke of increases in the 35- to 50-percent range, which required them or necessitated their action in moving to new carriers or making alterations to their plan.

No. 2, employers, as Mr. Beard explained, have increasingly leaned to increasing the amount of deductibles in various amounts and application, not only for each employee but for the employee's dependents also.

Employers who have to meet costs and to continue to provide insurance have engaged in a general tightening-down of claims review and cost review, requiring second opinions in many cases and looking very carefully at the circumstances of admission to hospitals for surgeries or otherwise.

The employer also has been increasing employee education about medical costs and what causes them to rise, or what causes the cost to the employer to rise, asking employees in one case of those individuals surveyed to verify their own charges. This was in a company that has a profitsharing plan, so the employee could very readily relate to preserving the cost of employment above all.

As a last resort, we are finding that employers are requiring employees to contribute to their own plan or to increase the contributions that they may have been making. We do not see success in trying to persuade small employers who do not have health care for their employees to begin employee group plans because of the rapid escalation of health care costs in recent years, and the marginal profitability of most small business companies.

Likewise, we should not expect small businesses that currently have difficulty in providing health care for their own employees to embrace any scheme that asks them to share the cost of a universal system that aims to provide health insurance for employees who have no coverage at all.

Chairman ROCKEFELLER. John, what would you think if we were to find some way, as I have indicated throughout, to work with the insurance industry? For example, one of the things I noticed, as soon as the catastrophic bill failed in Congress, Medigap premiums just went roaring out of sight. Insurance companies in my judgment, took advantage of the bill's repeal. I cannot wait to hold hearings in the Finance Committee about this.

As I indicated earlier, I think there are some insurance companies, and I think the Pepper Commission is going to have something to do with this, that are looking at reform. They are looking at their policies toward those with preexisting conditions. They are looking at how they spread risk. These days, insurers tend to go for a certain niche, and chase people who are young and healthy as opposed to older people with more health problems.

Now, supposing we were able to pursue insurance reform. And suppose we were to find some way to offer either a subsidy or some help to small businesses so that they could offer health coverage.

In other words, unless you shift the whole burden of health coverage onto Government, business must maintain its responsibility for the people who are working.

So what if there was a system wherein there were subsidies for smaller industries, those who clearly have financial problems? That we recognize those problems, that we find some way to try and help with those problems?

I do not think there is a way of getting access to health care for everybody unless we do it through employers. At least that is the way I am thinking at this moment. Otherwise, we must go to something like national health insurance or some approach where all of the burden is placed on the taxpayers as a whole. That would never get through the Congress and would never get signed by the President of the United States.

Mr. HURD. I think most small employers——

Chairman ROCKEFELLER. They want to do it, don't they? If they could, they would want to.

Mr. HURD. I would think most small employers would if they found a coparticipation arrangement set up where you might bring two-thirds of those who do not provide insurance into a system where they provide some level of insurance for all employees. I think that could be accomplished.

Chairman ROCKEFELLER. Lee, don't you think that everybody has to share in this process, including workers?

Mr. BEARD. I don't think there is any way that can be avoided, Senator. I think everybody, as has been discussed earlier, is going to have to carry their own fair share of the load. I don't see any way to avoid it.

Chairman ROCKEFELLER. John, I didn't mean to cut you off, but actually I did, didn't I, so I guess I did mean to. You go right ahead.

Mr. HURD. The struggle of small businesses to provide basic benefits to employees, I believe, is a graphic reason that the Congress needs to take seriously any legislation that could impact on the financial stability of those businesses.

Lee probably won't agree with this but, for instance, the recent increase in the Federal minimum wage, while viewed by some as only token generosity by employers, likely will have a negative impact on the ability of the small businesses to provide new jobs, as well as to maintain health care benefits that they now provide employees.

Thousands of young people who terminate their education with high school, or less, probably become the minimum wage earners. Employers who cannot financially pay higher wages, add to their work force or provide health benefits to their employees are involuntarily participating in the regeneration of families who cannot provide a minimum quality of life, a part of which is health care.

So that is the challenge, it seems, of the Pepper Commission; to stop the regeneration of a deficient system of health care as well as provide for the perpetual care of generations past. Now, if that problem is controlled at the front end, it will be less costly later on, obviously.

Without pointing fingers, to conclude, Senator, our selection of national priorities needs to be improved. Speaking for the small businessman, when his tax dollars and the taxes of his employees leave their hands, they essentially lose identity with those dollars.

In view of that, and recognizing that health care is a critical national problem, this Commission might give attention to reviewing the Social Security system as a source of relief. Possibly one option could be to dedicate 1 percent of both the employer and employee tax to a special fund that would provide health care funds to working families, especially low wage earners, as supplements to regular health insurance programs or in instances where there is no insurance provided for the employee at all.

Thank you.

[The prepared statement of Mr. Hurd follows:]

West Virginia Chamber of Commerce

"Creating the Opportunity"

Statement of John D. Hurd, President, West Virginia Chamber of Commerce Presented to the Pepper Commission, December 13, 1989, Charleston, West Virginia.

My name is John Hurd, president, West Virginia Chamber of Commerce. I appear at the request of A. Michael Perry, Chairman of the West Virginia Chamber of Commerce.

As time allowed we surveyed several of the small business members of the State Chamber to determine their experience with health care costs in recent years. We are convinced that employers are making a valiant effort to provide, or to continue, a reasonable health insurance plan for their employees. Our small survey involved a manufacturer, a heavy equipment sales and service company, a lumber and building supply company and a department store. We asked them to track their health care expense over a five year period and we have prepared a brief account of the experience of each company, as an attachment to my statement. There appears to be a common thread of action that the collective group has taken in answer to rising costs. Those include:

1. Shopping frequently for carriers, becoming self-insured, when large rate increases are imminent. Several employers spoke of increases in the 35-50 percent range.

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2. Increasing deductibles in various amounts and application - for each employee to each employee and each of his/her dependents.

3. Tightened claims/cost review, require second opinion, preadmission certification.

4. Last resort of requiring employee to contribute to the plan or increasing employer contribution.

5. Increase employee education about medical costs; verifying own charges.

We see success in trying to persuade small employers who do not have health care for their employees to begin employee group plans because of the escalation of costs in recent years and, marginal profitability of small business companies. Likewise, we should not expect small business who currently have difficulty in providing health care for their own employees to embrace any scheme that asks them to share the cost of a universal system that aims to provide health insurance for employees who have no coverage at all.

The struggle of small business to provide basic benefits to its employee is a graphic reason that the Congress needs to take seriously any legislation that could impact on the financial stability of those businesses.

For instance, the recent increase in the federal minimum wage, while viewed by some as token generosity, likely will have a negative impact on the ability of the small businessman to provide new jobs as well as to maintain employee health care.

Thousands of young people who terminate their education with high school, or less, probably became the minimum wage earners. Employers who cannot financially pay higher wages, add to their work force, or provide

health benefits to their employees, are, involuntarily participating in the regeneration of families who cannot provide a minimum quality of life, a part of which is health care. So that is the challenge of the commission; to stop the regeneration of a deficient system of health care as well as provide for perpetual care of the older population. If that problem is controlled at the front end it will be less costly later on.

Without pointing fingers, our selection of national priorities needs to be improved. Speaking for the small businessman; when his tax dollars and the taxes of his employees leave their hands they lose identity with those dollars.

In view of that, and recognizing that health care is a critical national problem, this commission might give attention to reviewing the social security system as a source of relief. Possibly one option could be to dedicate one percent of both the employer and employees tax to a special fund that would provide health care funds to working families, especially low wage earners, as supplements to regular health insurance programs or in instances where there is no health insurance coverage at all.

Health Care History

of

Selected Small Businesses

In

West Virginia

The West Virginia Chamber of Commerce selected several small business that were begun and reside in West Virginia. All are family owned that have been maintained through successive generations.

#1-Stone & Thomas - a department store chain that started with a single store in West Virginia nab currently employs more than 1,000 in 20 stores in West Virginia, Kentucky, and Ohio. Except for 3 stores, all are "acquired" specialty shop.

Provide a self-insurance health care program.

Requires small percent co-payment by employees; company and employees payments put in an interest-bearing trust and gives employees options of coverage, including HMO's or Blue Cross where available.

Deductibles are required (since 1981).

There have been plan design changes in recent years.

Cost has risen at least 100% since 1981.

Close claims monitoring and preadmission certification.

#2-Walker Machinery Company - Charleston, WV.

400 employees; heavy equipment sales and service.

Has self-insured" its employees health care program since 1981.

Paid total cost of program (except $50 deductible), with cost

$800,000 in 1987.

Forecast costs would rise to $1.5 million in 1988 at which time decision was made to:

1. require employees to contribute $25 per month.
2. increase deductible from $50 to $150.
3. require employee to pay up to $1500 for costs after first 80% coverage.
4. tightened claims monitoring and preadmission requirements.

#3-J.H. Fletcher Company - Huntington, WV

124 employees; manufacturers small machinery for mining industries

Has profit sharing program as incentive for productivity and cost-savings program.

Has self-insured health care program, with cost escalation:

1985 - 10%

1986-87 - 41%

1988 - minus 11% resulted from claims monitoring, intense employee education program; require $250 deductible; pre-certification - employees are asked to make judgements on superfluous tests, x-rays, etc.

1989 - minus 24%

#4-Brown Lumber Company - Fairmont, WV

83 employees at 5 locations; retail lumber and building supplies

(total employees reduced from 120 in 1987 at seven locations)

Provides employer/employee health care plan with 50/50 cost savings

Since 1985 because of rising costs, company has:

1. Increased deductible from $100 to $300.
2. Changed plan twice in the face of 30-50% premium increase

and per employee cost was $77.60 per month in 1985, now at $73.75. Family cost $194.47 in 1985, now $213.95.

3. Tighter claims monitoring, second opinion, preadmissions testing.

Company program has benefitted from employees (because of personal costs) leaving plan in favor of spouse coverage under government-paid programs at little or no cost to recipients.

West Virginia Chamber of Commerce

December 13, 1989.

Chairman ROCKEFELLER. John, thank you very much.

I apologize to all of you that the Pepper Commission is not authorized to provide lunch.

Kayetta, we welcome your testimony and I am sorry that you had to wait so long.

STATEMENT OF KAYETTA MEADOWS, PRESIDENT, WEST VIRGINIA EDUCATION ASSOCIATION [WVEA]

Ms. MEADOWS. Thank you. There are advantages to being last. I know the end is near. When you are the last person on the last panel, then we are almost finished. I have had the benefit of listening to the other panelists, a somewhat captive audience, and I do appreciate that.

Senator Rockefeller, I am Kayetta Meadows, president of the West Virginia Education Association, the largest education employee organization in West Virginia. We are nationally affiliated with the National Education Association.

On behalf of our 17,000 members, WVEA welcomes the opportunity to present our views on health care issues facing the United States.

Frankly, health care is one of the most important crises that we face today. Unfortunately, I have not brought you a suitcase full of solutions to resolve these problems, but I do want to underscore the need for a comprehensive health care plan in West Virginia as it affects public employees.

West Virginians are acutely aware of the impact that the skyrocketing cost of health care is having on our society. Recently, the Communications Workers of America were forced to go on a strike against a local Baby Bell Co. in an effort to preserve their health insurance benefits and prevent the company from shifting increasing costs onto the employee. Fortunately, that strike was relatively short and successful.

A far less fortunate situation is occurring with the United Mine Workers of America [UMWA] and the Pittston Coal Co. I am sure that many of you will recall that during the 1970's and early 1980's the coal fields were a troubled place. Nationally, contracts between the UMWA and Bituminous Coal Operators of America were settled only after long, bitter strikes.

Even after national contracts were reached, there were often wildcat strikes over local labor disputes. The reliability of coal deliveries to export and domestic consumers were of utmost concern.

The election of Rich Trumpka to president of the UMWA changed this situation dramatically. President Trumpka was successful in negotiating two national coal contracts without a coal strike. Wildcat strikes disappeared. The UMWA and President Trumpka took great pride, and deservedly so, in restoring peace, productivity, and predictability to the coal fields of America.

These accomplishments have been shattered by the actions of the Pittston Coal Co., and the principal obstacle of settling the Pittston strike is the issue of health care benefits, in particular, the health care benefits paid to retirees.

These two recent cases in West Virginia, and there are certainly many more cases that are similar around the country, have led at

least some observers to note that health care costs are a severe determent to good labor management relations.

West Virginia school employees have not been exempt from the problems of increasing health care cost. In West Virginia, all school employees and all public employees are covered by the Public Employees Insurance Agency or PEIA, and let me quickly review what has happened with PEIA over just the last 2 years.

Prior to 1988, the deductible for employees insured with PEIA was limited to $100 annually per individual. During the 1988 legislative session, deductibles were raised to $250 annually for a single plan and $400 annually for a family plan. During the same time, teachers were not provided a salary increase.

The legislature did increase the sales tax from 5 cents to 6 cents per 1 dollar's worth of sales. The revenue from this increase in sales tax was dedicated solely to PEIA. The legislature also borrowed $30 million in order to keep up with the increasing cost of PEIA.

West Virginia's constitution prohibits us from having more than a casual deficit.

In short, during 1988, we decreased teacher salaries for every teacher who utilized health care services, we taxed every man, woman, and child in this State in order to keep up with the increasing health care cost, and since $30 million by some people's estimates is not a casual deficit, we may have even violated the State's constitution. But we had hoped that this would be enough to cure the medical care cost problem for years. It was not.

During 1989, additional action was taken to try and stop the flood of increased cost. The legislature froze reimbursements to hospitals for a 2-year period. The legislature required that PEIA enter into a preferred provider contract with physicians and prohibited physicians from being reimbursed at any higher than the 80th percentile.

Once again, the legislature borrowed money to pay medical claims and this time it wasn't $30 million but $92 million. To place that $92 million into perspective, had this money been free to be redirected into salaries, teachers would have received a 20-percent salary increase. Instead, West Virginia teachers received less than a 5-percent salary increase on the average.

And finally, PEIA instituted an additional deductible on prescription drugs and lowered the price that PEIA would reimburse to pharmacies. We had hoped that this would be enough to cure the medical cost problems for years and apparently, it is not.

Recently, PEIA has announced that they will seek a 1½-percent salary decrease for all teachers, school service personnel, and public employees beginning next year in order to pay for possible future increases in health care cost.

Should this proposal be successful, and we sincerely hope that it will not be, teachers who were paying deductibles of $100 annually per individual prior to 1988 will be paying deductibles and premiums of up to $650 annually for a single plan and $950 annually for a family plan. Copayments on x rays, lab tests, and major medical expenses would drive these out-of-pocket expenses even higher.

Regardless of the final decision on premiums, what additional steps can West Virginia take? We have shifted cost onto employees,

we have raised taxes in order to fund health insurance benefits, and we have tried some cost containment measures. Yet, we continue to have severe problems finding enough money for the ever-increasing costs of health care. We are to the point that we feel that you cannot print the money fast enough to keep up with the cost of health care.

The need for a comprehensive national health care program is clear and compelling. The WVEA supports a program which will provide universal health care for all Americans. Currently of the estimated 31 to 37 million Americans who lack health insurance, 350,000 are West Virginians.

Most of these West Virginians work. Their employers do not provide health insurance benefits or they deny benefits to those who work less than full time. It is not that these individuals do not get sick or do not need health care.

The lack of primary health care and the delay in diagnosis exacerbates their health care needs. Frequently the emergency room, one of the most expensive forms of health care delivery, is the first point of contact for health care for uninsured individuals.

The cost for this uncompensated health care is passed on to third-party health insurance companies. Would we not be better off by providing reasonable preventive care paid with tax dollars rather than hiding these costs in insurance premiums. Clearly, we would.

One component of a comprehensive national health care program should also include long-term care for the elderly and disabled. Providing these medical services should be a national priority.

Senator Rockefeller, we need a national solution to skyrocketing health care costs. Passage of a comprehensive national health care plan or program which provides both long-term health care and universal health care coverage could be the most important pro-education legislation passed in the 1990's.

We thank you for the opportunity to share our views with you.

[The prepared statement of Ms. Meadows follows:]

WEST VIRGINIA EDUCATION ASSOCIATION TESTIMONY BEFORE THE UNITED STATES BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE

Presented by: Kayetta Meadows, WVEA President

Charleston, West Virginia
December 13, 1989

WEST VIRGINIA EDUCATION ASSOCIATION TESTIMONY BEFORE THE UNITED STATES BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE

Senator Rockefeller, members of the United States Bipartisan Commission on Comprehensive Health Care, my name is Kayetta Meadows and I am the President of the West Virginia Education Association, the largest education employee organization in West Virginia - nationally affiliated with the National Education Association. On behalf of our 17,000 members, WVEA welcomes the opportunity to present our views on health care issues facing the United States. Frankly, health care is one of the most important crises that we face today.

West Virginians are acutely aware of the impact that the skyrocketing cost of health care is having on our society. Recently, the Communications Workers of American were forced to go out on strike against the local baby Bell company in an effort to preserve their health insurance benefits and prevent the company from shifting increasing costs onto the employee. Fortunately, that strike was relatively short and successful.

A far less fortunate situation is occurring with the United Mine Workers of American [UMWA] and the Pittson Coal Company. I'm sure that many of you will recall that during the 1970's and early 1980's the coal fields were a troubled place. National contracts between the UMWA and the

Bituminous Coal Operators of American [BCOA] were settled only after long bitter strikes. Even after national contracts were reached, there were often wildcat strikes over local labor disputes. The reliability of coal deliveries by export and domestic consumers were of upmost concern.

The election of Rich Trumka to President of the UMWA changed this situation dramatically. President Trumka was successful in negotiating two national coal contracts without a coal strike. Wildcat strikes disappeared. The UMWA and President Trumka took great pride -- and deservedly so -- in restoring peace, productivity and predictability to the coal fields of America.

These accomplishments have been shattered by the actions of the Pittson Coal Company. The principal obstacle of settling the Pittson strike is the issue of health care benefits and, in particular, the health care benefits paid to retirees.

These two recent cases in West Virginia -- and there are certainly many more cases around the country -- have led at least some observers to note that health care costs are a severe determent to good labor/management relations.

West Virginia school employees have not been exempt from the problems of increasing health care costs. In West Virginia all school employees and all public employees are covered by the Public Employees Insurance Agency [PEIA].

Let me quickly review what has happened with PEIA over just the last two years.

Prior to 1988, the deductible for employees insured with PEIA was limited to $100 annually per individual. During the 1988 Legislative session, deductibles were raised to $250 annually for a single plan and $400 annually for a family plan. During this same time, teachers were not provided a salary increase. The Legislature did increase the sales tax from five cents to six cents per one dollar's worth of sales. The revenues from this increase in sales tax was dedicated solely to PEIA. The Legislature also borrowed $30 million in order to keep up with the increasing costs of PEIA. West Virginia's Constitution prohibits us from having more than a "casual deficit." In short, during 1988 we: a) decreased teachers' salaries for every teacher who utilized health care services; b) we taxed every man, woman and child in this state in order to keep up with increasing health care costs; and c) since $30 million is, in our opinion, more than a casual deficit, we probably violated the state's Constitution.

We had hoped that would be enough to "cure" the health care cost problem for years. It was not.

During 1989, additional action was taken to try and stop the flood of increased costs. The Legislature froze reimbursements to hospitals for a two-year period. The Legislature required the PEIA enter into a preferred provider contract with physicians and prohibited physicians

from being reimbursed at any higher than the 80th percentile. Once again the Legislature borrowed money to pay medical claims. This time it wasn't $30 million, but $92 million. To place that $92 million into perspective, could this money have been redirected into salaries, teachers would have received almost a 20 percent salary increase. Instead, West Virginia teachers received less than a 5 percent salary increase on the average. Finally, PEIA instituted an additional deductible on prescription drugs and lowered the price that PEIA will reimburse to pharmacies.

We had hoped that this would have been enough to "cure" the health care cost problem for years. Apparently, it is not.

Recently, PEIA has announced that they will seek a 1-1/2 percent salary decrease for all teachers, school service personnel and public employees beginning next year, in order to pay for possible future increases in health care costs. Should this proposal be successful -- and we sincerely hope that it will not be -- teachers who were paying deductibles of $100 annually per individual prior to 1988 will be paying deductibles and premiums of up to $650 annually for a single plan and up to $950 annually for a family plan. Co-payments on X-rays, lab tests and major medical expenses could drive these out of pocket expenses even higher.

Regardless of the final decision on premiums, what additional steps can West Virginia take? We have shifted costs onto employees, we have raised taxes in order to fund health insurance benefits, and we have tried some cost containment measures. Yet, we continue to have severe problems finding enough money for the ever increasing cost of health care.

The need for a comprehensive national health care program is clear and compelling. The WVEA supports a program which will provide universal health care for all Americans. Currently, of the estimated 31 to 37 million Americans who lack health insurance, 300,000 are West Virginians. Most of these West Virginians work. Their employers do not provide health insurance benefits or they deny benefits to those who work less than full time. It's not that these individuals don't get sick or need health care. The lack of primary health care and the delay in diagnosis exacerbates their health care needs. Frequently, the emergency room -- one of the most expensive forms of health care delivery -- is the first point of contact for health care for uninsured individuals. The cost for this uncompensated health care is passed on to third party health insurance companies. Would we not be better off by providing reasonable preventive care, paid with tax dollars, rather than hiding these costs in health insurance premiums? Clearly we would.

One component of a comprehensive national health care program should also include long-term care for the elderly and disabled. Providing these medical services should be a national priority.

Senator Rockefeller, members of the Pepper Commission, we need a national solution to skyrocketing health care costs. Passage of a comprehensive national health care program which provides both long term health care and universal health coverage could be the most important pro-education action passed during the 1990's. Thank you for the opportunity to present our views. I'll be glad to answer any questions.

Chairman ROCKEFELLER. Thank you, Kayetta.

Let me just say to each of you that we have been through a very interesting experience in Washington with legislation called catastrophic health care. The program was rejected.

The rejection taught us lessons. There are a lot of health care needs in this country.

We are talking about tens and tens of billions of dollars. Everybody wants to see access to care, nobody wants to have to pay more. Workers don't want to have to pay more, seniors don't want to pay more, business doesn't want to have to pay more, teachers don't want to have salaries reduced, much less pay more. You indicated in your own testimony some indication of getting salaries reduced.

We are all going to have to share in this job and the Pepper Commission is absolutely determined to find a way to provide access, to provide long-term care, to do it through a system in which we also control cost because that has to happen. Medicare cannot continue to increase at 17 percent a year, or else we are going to have to do something draconian to curb health care spending.

The Nation is broke. We spend $200 billion every year, right now, just paying the interest on the Federal debt to banks, most of them foreign. So if we are going to do this, and we are going to do it, it is going to be painful. I want that understood. This is not a Commission of happy news. It is a Commission of sincere commitment to resolving problems.

I think the basis of this country has to be good education and good health and that does not come without cost. We are all going to share in that cost. The Pepper Commission is gathering in Washington, as I indicated earlier, tomorrow morning at 8 a.m. The members are coming back from all over the country to spend 8 hours in deliberation. We have got more sessions scheduled for January and February. This Commission has really worked hard over the summer. People have not noticed it particularly but we have really been working hard.

We are going to put out a solution which is going to be the fairest, most equitable, most comprehensive and humane solution that I think anybody can come up with. I really believe that. It is my determination as chairman that we are going to propose a program that also can pass the Congress and survive the President's signature.

We have to deal with realities. How can we get it past the House? How can we get it past the Senate Finance Committee, then Ways and Means, and the Energy and Commerce Committee on the House side? And if we get it through there, can we get it by the President? Nothing makes any difference unless it gets into law. Nothing happens unless it becomes public law. So that is our challenge.

You-all, and when I say "you," all of those who have preceded you, as well as yourselves, have contributed enormously to this process. I am very proud that we have had a hearing and such a good one, a useful one, a constructive one, an honest one, and at times, a very emotional hearing, here in my State of West Virginia. I feel very proud about that.

We are enormously challenged on the Pepper Commission. We will rise to the challenge and we will deliver to the Congress and to the President and to the 50 Governors a program which will, in fact, bring access to health care to every American and provide long-term care to every American who needs it.

I declare this hearing adjourned.

[Whereupon, at 2:08 p.m., the hearing was adjourned.]

APPENDIX

CANCER AND THE POOR: A REPORT TO THE NATION

FINDINGS OF REGIONAL HEARINGS
CONDUCTED BY
AMERICAN CANCER SOCIETY

89-3M-No. 0216

CANCER AND THE POOR: A REPORT TO THE NATION

Findings of Regional Hearings Conducted by American Cancer Society

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APPENDICES 35

A. Testifier Profiles
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American Cancer Society
1599 Clifton Road, N.E., Atlanta, Georgia, 30329

1. INTRODUCTION

Americans can be proud of the progress our country has made against cancer. Through advances in research and medical care, and the contributions of thousands of volunteers involved in cancer education, we have dramatically increased the survival rate for many cancers. Today, cancer survivors and their families can live active and fulfilling lives.

For the nation's poor, however, there is little to celebrate. Millions of Americans living in poverty are not reaping the benefits of advances in cancer prevention, detection and treatment. For these Americans, a diagnosis of cancer is most often a needless death sentence.

This inequity was vividly conveyed by poor Americans and the people who serve them during a series of hearings the American Cancer Society conducted across the country in the spring of 1989. Disadvantaged whites, blacks, Hispanics, American Indians and older people described with passion their frustrations in seeking and obtaining care, their battles with insensitive providers and with bureaucracies which create unnecessary obstacles to care. They talked of their fears about cancer and the devastating impact cancer had on them and their families.

We heard from many who had fought the system against all odds and won. They were survivors. But they paid a price which far exceeds that exacted from most cancer patients. Many of these hard-working Americans were driven into poverty by their treatment. They lost their jobs. They gave up their homes to pay for care. And in seeking help with little ability to pay for it, they sacrificed their dignity. After all this, they are left with medical bills they may never be able to fully pay.

As a nation, we must turn our attention to those who lack access to quality healthcare. They are the 37 million uninsured and those whose health insurance is inadequate. They are people who do not live near health facilities which are capable of -- and willing to -- serve their needs. They are people who are not now reached by cancer education efforts: the 39 million Americans living below the poverty level and the millions of others who are trying to cope on the brink.

The American Cancer Society is committed to helping people who are at greatest risk of dying from cancer. These hearings have provided valuable insights to the problem and reinforced the urgency of moving forward to develop strategies for addressing it.

The problem is one which we all share. There are people who are poor today who will become middle class. And there are middle class people who will become poor. The circle of poverty is not a closed circle. How many of us could miss next month's paycheck and not fall into the circle of poverty? Let us not view poverty as a problem of others. Let us see reflections of ourselves in the poor.

Harold P. Freeman
President
American Cancer Society

2. PREFACE

For 76 years, the American Cancer Society (ACS) has been the public's advocate for cancer control. It is our mission to eliminate cancer as a major health problem by preventing cancer, saving lives from cancer and diminishing suffering from cancer through research, education and service.

That is why we have turned our attention to the problem of cancer in the poor. ACS has mounted a special initiative to understand and address the cancer prevention and control needs of the people at greatest risk of dying from cancer. In addition to conducting hearings around the country, we have conducted extensive research on the subject.

By calling attention to the problem, we hope to serve as a catalyst to change. We are asking the many organizations that are in a position to affect the health status of poor Americans to join with us in ending this needless discrimination and giving poor Americans an equal opportunity to survive cancer.

The leadership of the American Cancer Society is paying close attention to the findings of these hearings and will be developing specific programs to respond to the needs identified. We have already committed $2.8 million in seed funds for national demonstration programs to fund community organizations to deliver cancer prevention and detection services for the poor.

We hope that this program, combined with the activities in which many of our divisions are now engaged or are planning to undertake, will help to provide poor Americans with hope that something can be done, and is being done, to help them.

But our efforts alone will not turn the tide against the overwhelming problem of limited access to care and information. To do this, our nation desperately needs improvements in public policy, in public and professional education, and in delivery of health services for prevention, detection, treatment and rehabilitation of cancer and other diseases.

We urge health policymakers, advocacy groups, professional societies, employers, research institutions and others to help develop and implement comprehensive strategies for reform. And we pledge the commitment and resources of the American Cancer Society to make a meaningful contribution to this effort.

Kathleen J. Horsch
Chairman of the Board
American Cancer Society

3. AMERICAN CANCER SOCIETY HEARINGS ON CANCER AND THE POOR

The American Cancer Society (ACS) is the national voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives from cancer and diminishing suffering from cancer through research, education and service.

A major ACS priority is helping people who are at greatest risk of dying from cancer. A recent ACS study confirmed that poor Americans -- including economically disadvantaged whites, blacks, Hispanics and American Indians -- have higher rates of mortality from cancer than other income groups.

To better understand the dimensions of this problem and to identify possible solutions, the Society sponsored a series of hearings across the country in May and June 1989. These hearings are part of an special ACS initiative to serve the disadvantaged.

Sixty-eight disadvantaged people and 94 professionals who work with the disadvantaged presented testimony at seven regional hearings. In addition, written or video testimony was submitted by 76 individuals unable to participate. (See Appendix A for a complete listing of testifiers and Appendix B for a listing of people who submitted written or video testimony.)

Hearings were held in Atlanta, GA; Jackson, MS; Newark, NJ; St. Louis, MO; El Paso, TX; Sacramento, CA; and Phoenix, AZ. People from throughout these regions presented testimony, with 47 states and territories represented.

A panel chaired by ACS President Dr. Harold Freeman listened to testimony and questioned presenters. In addition to Dr. Freeman, panelists included ACS Chairman of the Board Kathleen J. Horsch and other ACS leadership, representatives of the National Cancer Institute and the Centers for Disease Control, and policymakers from the region. (See Appendix C for complete listing of panelists.)

The hearings were supported by regional committees made up of ACS volunteers and representatives of organizations serving the disadvantaged. These committees helped to identify and recruit individuals to testify and prepared and presented testimony on behalf of the ACS divisions in the region. (Appendix D includes a list of regional committee members. Appendix E provides a list of categories for regional committees and testifiers.)

This Report to the Nation reflects common themes and issues which emerged from the hearings. Complete transcripts of the hearings and copies of all written testimony were compiled by ACS and are maintained at ACS headquarters in Atlanta, GA.

4. KEY FINDINGS

Poor people lack access to quality healthcare and are more likely than others to die of cancer.

This stark reality was revealed through the words and experiences of poor people around the country during the American Cancer Society Hearings on Cancer and the Poor. Through more than 45 hours of testimony on a wide range of subjects, the dimensions of this problem were exposed.

Following are common themes which emerged from the hearing process, along with quotes from testimony which capture the essence of the issue in the words of the people who experience these problems first hand. Each of these subjects is explored in greater detail in subsequent sections of this report.

4.1 Poor people endure greater pain and suffering from cancer than other Americans.

> "For most of the poor, the emergency room becomes a primary place of healthcare going from one crisis to the next."
>
> --Dr. Janelle Goetcheus, Washington, D.C.

There is substantial evidence that the poor are more likely to be diagnosed with cancer when the disease is advanced and the treatment options are significantly more limited. Poor patients are forced to accept substandard treatment and to endure assaults on their dignity to obtain needed care.

4.2 Poor people face substantial obstacles in obtaining and using health insurance and often don't seek needed care if they can't pay for it.

> "Instead of battling the disease, I'm battling the whole system trying to figure out what I can do."
>
> --Barbara Johnstone, Grand Junction, CO

At least 37 million poor and near poor Americans cannot afford private health insurance and are ineligible for public assistance. Those who are insured are often financially devastated by the substantial gaps in coverage. Delays in eligibility, and bureaucratic snags in processing claims, cause poor patients to suffer added hardships.

4.3 Poor people and their families must make extraordinary personal sacrifices to obtain and pay for healthcare.

> "We have a goal. We're not trying to finance a car, we're not trying to buy a house. We're trying to save our kid's life. I don't need a lot of things . . . I just need Emma's healthcare paid for."
>
> --Walt Seaver, Colusa, CA

Many poor Americans are forced to choose between paying for food and shelter and paying for care. To find and pay for cancer treatment for themselves or their family members, poor Americans may sacrifice their homes, their jobs and even their families. Cancer drives many middle class Americans into poverty.

4.4 Cancer education and outreach efforts are insensitive and irrelevant to many poor people.

> "I needed to see someone who had lived through it. I didn't care about the words. I needed to see someone standing there. And they said . . . they couldn't find anybody who was like me."
>
> --Judith Hadley, Portland, OR

The burden of daily survival weighs heavily on the poor, and health concerns are often ignored until pain is significant. Cancer education efforts often ignore this reality and are thus largely irrelevant. This problem is compounded by the lack of educational materials which appeal to different cultures and a lack of volunteers in poor communities.

4.5 Fatalism about cancer prevails among the poor and prevents them from gaining quality healthcare.

> "People avert their heads, lower their voices . . . it is a sentence to die."
>
> --Joan Ross, Huntington, WV

Based both on limited knowledge and on the reality of their encounters with the healthcare system, poor Americans mistakenly believe that there is no hope of surviving cancer. Fears and misperceptions about cancer prevent many poor Americans from seeking needed care.

5. CHALLENGES TO SERVING THE CANCER NEEDS OF POOR AMERICANS

Government and private organizations at national, state, and local levels should forge a partnership to help poor Americans conquer cancer.

This was the plea of disadvantaged people and professionals who serve them in one city after another. The problems affecting cancer and the poor are many and multifaceted. To address them effectively, testifiers called for reforms in public policy, reforms in the healthcare system, and more private initiative to serve the poor at the community level. Most importantly, they called for increased collaboration among the many organizations who are in a position to have a positive influence on the lives of the poor.

While the scope of the American Cancer Society hearings was limited to cancer and its influences, the findings are broadly relevant to the American healthcare system. These hearings have emphasized that to have an impact on cancer, our nation must address the underlying problem of delivering health services to people without means.

While pointing to many significant problems, testifiers also challenged the American Cancer Society, policymakers and other organizations serving the poor to take actions which would move America closer towards solutions. Following are specific challenges which emerged from testimony.

- Assure that cancer prevention, detection, treatment and rehabilitation services are available and accessible to all who need them, regardless of the ability to pay.
- Improve cancer prevention and early detection among poor Americans to eliminate unnecessary pain, suffering, and death.
- Undertake aggressive educational efforts to counteract fatalism, overcome fears and enable poor people to reduce cancer risk.
- Improve and expand public and private assistance for the poor, including health insurance.
- Develop cancer education materials and outreach programs which are culturally sensitive, understandable and relevant to poor people.

- Establish patient advocates and referral services to help poor patients navigate the health system and manage personal problems which result from cancer detection and subsequent treatment.

- Involve community organizations serving the poor and poor people themselves in cancer education and patient advocacy programs.

- Train healthcare providers to be more sensitive and understanding of the needs of poor patients and to better serve their needs.

- Expand availability of and accessibility to health services for poor people in all areas which are now underserved.

- Conduct research to further document the scope of the problem and identify effective interventions.

The American Cancer Society is committed to addressing the needs of disadvantaged Americans. Through its Special Initiative on the Socioeconomic Disadvantaged, the Society has launched a number of innovative programs to serve this population. ACS is using the findings of these hearings along with other research to further develop specific programs and policy positions which will respond to these challenges.

6. PROFILE OF VULNERABLE POPULATIONS

Disadvantaged Americans come from many different cultural and ethnic groups including millions of poor white people. There are 38.7 million Americans living below poverty level, according to the U.S. Census Bureau (1986). This includes 23.2 million poor whites, 9.6. million blacks, 5.1 million Hispanics and .8 million American Indians and Asian Americans.

Although the greatest poverty is found in the South, poor people live in every area of our country.

Many poor Americans are working yet cannot raise themselves from poverty. In 1986, fully half of the nation's seven million heads of poor households worked at least part-time.

This statistical profile of the economically disadvantaged does not adequately capture the populations most vulnerable to cancer, however. The ACS Hearings on Cancer and the Poor revealed that vulnerable populations include many people who are living near the poverty level ($11,203 annual family income for a family of four), whose health problems trigger or compound financial deprivation, or who are not adequately reflected in the U.S. Census, such as migrant workers and the nation's homeless.

While the hearings revealed some problems unique to special population groups, there were many common themes expressed. Common themes are explored further in this report. Following is a brief profile of some of the characteristics of the people whose experience with cancer is also related to cultural or societal conditions which are distinct from those of other poor Americans.

6.1 Homeless People

An estimated three million people in urban and rural areas across America are homeless. While the experiences of the woman who sleeps in a cave in rural West Virginia are vastly different from those of the man who spends the night on a subway grate in Washington, D.C., both of these people are forgotten by the American health system.

Homeless people are particularly traumatized by the healthcare system which discharges patients "quicker and sicker." Those who are successful in gaining emergency care are often shuttled back and forth between shelters ill-equipped to serve recovering or seriously ill people and hospitals unable to provide long-term comprehensive care.

Health professionals working in homeless shelters frequently encounter people suffering from cancer and other chronic diseases which are so far advanced that little can be done but control the pain.

6.2 Migrant Workers

The working poor and those on the brink of poverty include farm workers who follow the seasons from one area of the country to another to harvest the crops. These workers and their families are particularly vulnerable to environmental risks associated with pesticide application and prolonged exposure to the sun.

Public health services in small agricultural communities are seriously strained by the seasonal influx of workers. In addition, migrant workers are especially taxed by the lack of continuity of care.

Among migrant workers are many illegal aliens. These individuals are reluctant to seek public assistance for fear of being forced to leave the country.

6.3 Recent Immigrants

Hundreds of thousands of immigrants come to the United States every year, many unable to speak or understand English well. While the language barrier poses perhaps the greatest problem for these new Americans in gaining access to health information and care, they also experience added problems trying to understand and use already confusing public assistance programs.

Many immigrants bring with them strong cultural values, and attitudes towards cancer and cancer treatment which reflect how the disease is treated in countries with significantly less advanced healthcare systems.

6.4 American Indians and Native Alaskans

This diverse group of people includes over 200 separate and independent nations, or tribes, in urban, rural and reservation settings throughout the United States. While this diversity makes it difficult to generalize about American Indians and Native Alaskans, there are a number of shared beliefs and values which affect their understanding of and reactions to cancer.

Alcoholism, diabetes and hypertension are common health problems among American Indians. While an Indian Health Service hospital or clinic is located on every reservation, American Indians also believe strongly in traditional healing, reflecting a desire to work in harmony with natural forces rather than seeking to control them.

The typical family structure for American Indians is a complex intergenerational one, rather than a nuclear family, and this larger support group helps provide care and influences decisions about personal health.

6.5 Hispanics

Hispanic Americans include people from Mexico, Puerto Rico, Cuba, Central and South America. This culturally-varied group shares some common values which affect its perceptions of cancer.

Many Hispanics rely on an extended family to provide support in times of financial and emotional stress. Men generally dominate within society and the family unit and express their "machismo" by exhibiting control. This may be manifested in a reluctance to acknowledge early warning signs of illness or to seek care.

Almost one million Hispanic Americans do not speak English at all, and as many as two million others have only a limited command of the language. These people are virtually ignored by the cancer education system.

6.6 Blacks

ACS surveys revealed that awareness and use of cancer screening tests is lower among blacks than whites.

A National Cancer Institute study of cancer rates over several decades also shows that both the cancer incidence rate and the cancer death rate are higher for blacks than for whites.

The extended family is also important to black Americans, although its fibers have been weakened by numerous social ills. Nearly one-third of black families are headed by women.

Many blacks are aware of their increased risk of hypertension and see cancer as a problem more likely to face whites. They tend to be fatalistic about their chances of getting cancer and pessimistic about the prospect of survival.

6.7 Whites

Nearly 24 million whites in the U.S. live below the poverty level, making up 63% of the nation's poor.

Poor whites are disproportionately located in rural and Appalachian America. Here, low literacy, poor diet, high tobacco use, lack of available transportation and sheer distance to scarce medical services combine with lack of money or insurance to prevent poor whites from gaining adequate healthcare.

Proud and independent, poor whites resent intrusion into their privacy, and don't seek social services, screenings and other health assistance when they can't pay for them. They have few ties to any institutions other than the church and their family.

6.8 Older People

With people 85 and older the fastest growing segment of our population, it is not surprising that at least 3.5 million older people are among the nation's poor. The need for acute and long term care increases with age, yet older people often find themselves unable to pay for care or for adequate insurance coverage. Many who have serious health problems are too young to qualify for Medicare (65+) and too financially secure to quality for Medicaid.

With increases in longevity, many older adults find themselves financially unprepared for their retirement years. A serious illness or the need for long term care often causes older adults to spend down to poverty in order to qualify for health benefits.

Coping with serious illness is a particular problem for older women, many of whom live alone.

Older people may ignore warning signs of cancer assuming aches and pains are part of the normal aging process.

7. CRITICAL ISSUES AFFECTING CANCER AND THE POOR

The scope of written and oral testimony presented at the American Cancer Society Hearings on Cancer and the Poor was extensive. This Executive Summary uses representative testimony to describe and elaborate on key findings.

7.1 Poor people endure greater pain and suffering from cancer than other Americans.

Even for individuals with access to quality healthcare and the means to pay for it, the prospect of cancer is frightening. Cancer patients and their families experience great anxiety in undergoing diagnosis and treatment regardless of their socioeconomic status.

For the poor, hardships normally associated with cancer diagnosis and treatment are compounded by their encounters with a healthcare bureaucracy seemingly incapable of providing adequate care to the most needy. As a result, poor Americans endure unnecessary pain and suffering and have more dismal prospects for survival.

The crux of the problem is a prevalence of late diagnosis. The American Cancer Society estimates that about 178,000 people with cancer will probably die in 1989 who might have been saved by earlier diagnosis and prompt treatment. The hearings provide substantial evidence that many of these needless deaths will occur among the poor.

Many poor people are diagnosed with cancer when the disease is advanced and treatment options are more limited. While this problem is due in part to a low awareness of the warning signs of cancer, and to the lack of funds to pay for care, the incidence of late diagnosis among the poor is also a reflection of inadequacies in the healthcare system. According to testimony, it is a system which discourages preventive healthcare, which encourages patients to wait until their health problems are virtually unbearable before seeking care, and which imposes unnecessary delays in diagnosis and treatment.

7.1.1 Seeking care in crisis

"For most of the poor, the emergency room becomes a primary place of healthcare going from one crisis to the next," said Dr. Janelle Goetcheus, a physician and Medical Director of the Health Care for the Homeless Project in Washington, D.C. She pointed to misperceptions about the quality of care provided to poor patients in teaching hospitals.

> If referrals are made for ongoing care, it is often to hospital outpatient clinics which are teaching-oriented and not patient-oriented. In this setting, the patient will not only experience long waits, be shuffled from one specialty clinic to another, but will also face seeing a different physician and trainee each visit.

In Dr. Goetcheus' view, "The poor have become the pawns of the American medical education system."

Poor patients are frequently "dumped" at institutions such as Cook County Hospital in Chicago which serves the medically indigent. Dr. David Ansell is director of the Breast Cancer Detection Program at the hospital's General Medicine Clinic. He described a cancer patient who arrived at the clinic with a note addressed "To whom it may concern." The note described the patient's condition in a single paragraph and alerted the clinic that she would require chronic care and medications indefinitely.

> There's no phone call, no chart, no medical records . . . This scenario is repeated daily. Sometimes the patients come with pieces of paper, with notes from physicians. Sometimes they're simply told to come to Cook County. I wonder how many endure the indignity? I wonder how many get the message that the healthcare system does not care if you are poor? I wonder how many do not show up?

When poor people seek care, they find their basic assumptions about the humanity of the American health system are shattered. Virginia Peters described the ordeal of her husband, a Medicaid patient who died of cancer in Philadelphia, Pennsylvania.

> Charlie went from hospital to hospital to get help. All he wanted, and all I wanted for him, was to be as comfortable as possible, to receive whatever medical care was available to all persons, not just the wealthy, some kind of counseling from an outside group and to leave his life with dignity. Charlie didn't receive any of this.

Often, a poor person's prior experience with this health system will cause him to avoid seeking care urtil it is absolutely essential.

Once poor patients receive some treatment, they seldom have any continuity of care to assure a full recovery. This is particularly problematic in the treatment of cancer, which often requires a long-term treatment regimen.

In February 1988, Michael Robert Mack, a carpenter, underwent surgery in a public hospital in Arizona for basil cell carcinoma on his lip. Still recovering in May, he sought additional help to cope with severe pain.

> I saw many doctors through these months, a different one almost every visit, each time I have to explain the problem from beginning to end . . . The pain is intense . . . no one believes what I say and accuse me of just faking pain to get pain pills . . . I then sought medical needs through private practices, dentists, plastic surgeons, TMJ specialists, neurologists, etc. In November 1988, my left side of my face becomes paralyzed . . .

Eleven months after he first sought help for pain, and long after this health problems had become severe, Mr. Mack received needed care from a county hospital and is now undergoing radiation therapy.

7.1.2 Trying to maintain dignity

Many health professionals committed to serving the needs of the poor presented testimony at the ACS hearings. Their compassion and dedication to this underserved population was notable. Poor cancer patients and family members who testified described physicians they encountered who championed their cause or hospitals and other health systems which provided needed care regardless of their ability to pay.

The outstanding health professionals featured in testimony presented a stark contrast to the more common portraits which emerged of health providers who are insensitive to poor patients and destroy their dignity and self-worth

Cassandra Middleton, a single mother from St. John's Island, South Carolina, was shuffled between a local health clinic, a chiropractor in private practice, a hospital emergency room, and a medical university before being treated for a rare form of bone cancer at the National Institutes of Health in Washington, D.C. She echoed the experiences of other poor cancer patients in describing her treatment:

> Everybody is in such a rush like I'm not important. He just don't listen to what I have to say about me. Like hey, I don't care, you are just another cancer patient.

She summed up her ordeal poignantly: "They make me feel poor. I know I am, but then they make me feel like I am, too."

While others might demand better care, or more respect, poor patients assume that inferior care is the best they can expect. Marie Carter is a cancer survivor who now works as a patient advocate in Cook County Hospital in Chicago.

> This is very paintul, really, to feel that they look down on you when you poor. If you poor, you say, okay, well, I can't do any better. You angry, but you will accept it because there's nothing else you can do but accept. It's nowhere you can go, it's nothing you can do but accept whatever type of service is available to you.

7.1.3 Overcoming obstacles to early access

Some health providers have sought to make preventive health services more widely available to poor patients and to get them into the health system earlier. They, too, are shocked by the inadequacies of the system.

Prescilla A. DeRemer is an OB/GYN nurse practitioner with the San Francisco Community Clinic Consortium who refers women to the county hospital for mammograms.

> I am continually frustrated by the inaccessibility of services for poor women. At times I am told to call back in two months to make an appointment for a mammogram that will be scheduled another two to three months later. Within this time span I have lost my patient for follow-up; another high risk poor woman is unable to receive early detection and screening services.

In some cases, cancer screening tests are conducted and patients have nowhere to go for treatment. "Have we really done somebody a favor if we tell them you have a positive pap smear and they're unable to go for a follow-up biopsy or treatment?" asked Gordon Bonnyman, a legal services attorney from Nashville, Tennessee.

Cathy Bolia, a Vietnamese woman from Atlanta, Georgia, initially went to a doctor for help with a painful stomach ache. She was essentially put on hold until it was convenient for the doctor to see her.

> He didn't send me to the hospital yet because he said he was going on vacation and he wouldn't come back until a month later . . . He didn't refer me to another doctor or he didn't tell me whether or not this was serious. So I waited until he come back.

Ms. Bolia later underwent surgery three times for cancer of the colon. Her condition was significantly advanced by the time she received care.

7.1.4 Trading off the cost of prevention with the cost of care

It is the poor cancer patient who pays the highest cost of late diagnosis. But health professionals also pointed to the unnecessary cost these practices pose to the health system. Model programs now underway in communities around the country seek to establish the benefits of investing in preventive services for the poor.

"Public funds now being spent in the treatment of late stage disease could be redirected to support other cancer prevention and detection services for the poor," pointed out Dr. Mona Arreola, Assistant Director of the Cancer Center at the University of Tennessee at Memphis. Dr. Arreola, who is operating a mammography van to provide free screening to poor women, added ". . . the potential for medical cost saving alone clearly favors early diagnosis and outweighs the expense of a mobile unit at least two and a half times."

7.2 Poor people face substantial obstacles in obtaining and using health insurance and often don't seek needed care if they can't pay for it.

Poor people are acutely aware of the high cost of medical care and the inadequacy of public and private insurance to cover those costs. There are an estimated 37 million people in America without health insurance. Add to this figure people covered by public and/or private insurance whose coverage is inadequate and the estimated number of people unable to pay for needed care would soar.

Eligibility requirements for Medicaid, the government health insurance program designed to serve the poor, exclude many poor and near poor families. Less than 45 percent of the population below the federal poverty level are eligible for Medicaid. Access is further limited by restrictive definitions for eligibility categories.

Medicare, the health insurance program for people over 65, has a number of significant gaps, including lack of coverage for long-term healthcare.

Poor people partially covered by Medicaid, Medicare, or private insurance have no more confidence than the uninsured that their health needs will be met, according to testimony. When they seek to obtain benefits for which they are eligible or to process claims for reimbursement, they encounter a devastating bureaucracy that often leaves them stranded in poor health with bill collectors at the door.

The lack of coverage is an important contributor to the problem of late diagnosis, with many people afraid to seek care because they cannot pay for it. In addition, there are often delays in processing public benefits keeping patients from being treated in a timely manner.

7.2.1 Struggling to find care with no coverage

Many poor families are forced to accept the risk of being uninsured in order to pay daily living expenses. Marie Carter, a cancer patient in Chicago, described how she was caught without insurance.

> . . . (her husband) couldn't afford insurance and paying the rent and buying food, so we had to let the insurance go. I could tell them that I have cancer and I'm paying for insurance, but they would not accept that. If you're not able to pay the rent on time or you go to some of the grocery stores, they don't want to hear that sad story . . .

Whether they lack insurance because they are not eligible for health benefits or they simply can't pay premiums and still make ends meet, patients without insurance coverage are treated the same at the admitting room door. Many poor patients are turned away in critical condition.

Ellie Stafford, a 63-year-old from Whitleyville, Tennessee, was told by her surgeon she must have surgery immediately. She received a call from the hospital admitting office requesting a $5,000 cash deposit since she was uninsured.

With no money and no idea where to get it, she called her doctor. He confirmed it was urgent she receive care but said he knew of no way to arrange it for her. Six weeks later, when a social worker threatened to alert the local television station to her case, Mrs. Stafford was admitted for surgery.

Anna Walton, Director of Somerset Hospice in Somerset, Kentucky, described a recent phone call she received from an uninsured mother.

> I have three children, no husband. I work for $100 a week. I live in low-income housing. I do not have a medical card. I have a breast lump that is getting bigger every week. Who can I go to?

Ms. Walton explained the process for getting a mammogram and then, if necessary, undergoing treatment. The woman called back a few days later.

> To go to the doctor is $50. To get a mammogram is $100 because it's on sale this month at the local hospital. To get it read is another $50 to $100; and then my doctor said I need a biopsy if it's suspicious for cancer. I don't have any money. If I quit my job and wait until Welfare approves me so I can get a medical card it's going to be months. Meanwhile, how do I feed my children?

The prognosis for patients like this one in rural Appalachia is dismal. As Ms. Walton put it: "I don't have any answers. There are no services available for people like her."

Other rural areas report similar problems providing the poor with access to care. Alan Harks is an attorney from Vermont who has a civil poverty law practice.

> We do not have, in the rural northeast, an extensive system of public financing for acute care. We have a catch-as-catch-can system. We have a charity system. Charity does not guarantee access.

7.2.2 Suffering devastating delays in coverage

Delays in processing forms for benefit eligibility can have a devastating effect on patients and their family members. As an oncology social worker with Doctor's Hospital in Massillon, Ohio, Rita Schreffler helps patients apply for Social Security disability benefits and SSI.

> It is harder than ever to win these benefits for patients without the maximum amount of effort. Many are near death before they receive any benefits at all. I have seen middle class families reduced to poverty level, on welfare by the time their claim is approved. Those with a better income often just give up . . .

Virginia Solberg, Executive Director of the North Miami Foundation which serves the frail elderly, described the experience of Rosa and Wil, a couple in their early 60s.

> Within weeks of Wil's retirement, Rosa was diagnosed with cancer of the uterus. Although Wil and Rosa had $36,000 at the time of retirement, doctor bills wiped them out, leaving a balance due of $26,000 and expenses mounting daily. They were destitute and she died two days after her disability coverage became effective.

For these patients and their families, healthcare benefits are often too little, and too late.

7.2.3 Becoming impoverished to obtain health benefits

Many families experience a long, painful decline into poverty as they seek to obtain coverage for cancer treatment for prolonged periods. Hazel Rowan, the mother of a little girl with leukemia, described her struggle to find some means of paying for her daughter's chemotherapy. Initially insured through her husband's work, the Rowans lost their insurance when he switched jobs.

> I tried to get some kind of insurance from welfare. Nothing as long as Glen worked. Glen is a proud man and would not stop working to get on welfare . . . I try all insurance companies I see ads for. They want you to be off medicine for eight to ten years before they give you a policy . . .

Mrs. Rowan found a private policy but later had to go through the Oklahoma Insurance Commission to force them to pay covered expenses. The policy did not cover doctor's bills and other expenses amounting to more than $8,000.

"I wish there would be no cancer," Mrs. Rowan pleaded. "I guess that is too much to hope for. We have a very simple life, lots of love, but hardly no extras except birthdays and Christmas. We have to save as much as we can for hospital and doctor bills."

Poor people who are desperate to find a means to pay for care must consider rash moves which can destroy their families and their self-esteem.

Loma Phillips is a 59-year old homemaker suffering from cancer of the esophagus. Her story, as shared by her attorney, is startling.

> Mr. and Mrs. Phillips' total monthly income consists of his Social Security disability pension of $688 month. An increase in Mr. Phillips disability pension gave the family "too much money" to qualify for Tennessee's Medicaid program. The family has $76,000 in bills for cancer treatment. Their legal aid attorney has advised them to divorce after 40 years of marriage so that Mr. Phillips' disability pension will no longer be counted by the Medicaid program as income and will no longer exclude her from coverage.

Attorney Gordon Bonnyman directs a legal aid program to help patients beat the system and become eligible for benefits. He pointed to the inequity of a health system that forces many people to seek such legal services. "I'd like to put myself out of a job," he told the panel. "I don't think I ought to be working as a lawyer getting people access to basic healthcare."

7.2.4 Breaking through the bureaucracy

While many poor cancer patients persevere and are able to eventually get the care they need and to find a way to pay for it, there is no question that poor people need additional help to overcome the barriers to care.

"What most people really need is a guide to take them by the hand through this maze called the healthcare system," said Susan Constantine, a social worker in Rhode Island Hospital. Poor patients need someone to "provide applications . . . take them places . . . translate what the physician said in very simple language, make follow-up calls to make sure the patient and families have gotten in touch with services."

Some, like Rich Knoll, a cancer patient with three children, are lucky enough to have family members who can be advocates for better care. His wife, Lora, pleaded for help for poor patients who don't have the same kind of family support.

> I ran the interference. I was the one who said "This doctor is not making any sense. Let's get another opinion." He never would have survived it. Everybody needs somebody. And if they don't have family, somebody needs to be assigned to help get them through it . . . It's too stressful to have to worry about the logistics when they are already trying to deal with all the emotional aspects of cancer.

Testifiers called for the establishment of patient advocates to help poor families cope with the many problems of cancer care.

7.3 Poor people and their families must make extraordinary personal sacrifices to obtain and pay for healthcare.

For poor Americans, the burdens of daily living are substantial. Providing food, shelter and clothing for themselves and their families is a difficult challenge. A diagnosis of cancer compounds this struggle for survival and introduces new financial, physical, and psychological demands.

Walt Seaver of Colusa, California, described his five-year nightmare seeking some way to pay for care for his daughter with leukemia. This uninsured family's struggle to pay for care dominates their life.

> We have a goal. We're not trying to finance a car. We're not trying to buy a house. We're trying to save our kid's life . . . I don't need a lot of things. I just need Emma's healthcare paid for.

7.3.1 Driving patients into poverty

For many hard-working people, a cancer diagnosis can force them into poverty. Diana Mapes, a social worker with the Eastern Oklahoma Medical Center in LeFlore County, described the impact of cancer on some of their patients.

> They become unemployed and deeply in debt. They must ask for help from cold and indifferent public agencies, many times being told "no, you are not eligible." They are physically ill, emotionally drained and broke. They live from payday to payday normally. Suddenly, there is no payday.

Selma Schwartz of New Orleans, Louisiana, is typical of patients who lose their jobs as a result of their diagnosis. "At the time, I was employed as a live-in care person," she told the panel. "So when I had to quit, I not only lost my income but also my place to live."

Often a patient must choose between working and receiving benefits. Health and social benefit eligibility requirements serve as disincentives for poor cancer patients to work during treatment and recovery.

Adelaide Kaplan of Hempstead, New York, has suffered from cancer since 1967. She worked part-time and received some assistance from Aid to Families with Dependent Children.

> Because of my ongoing health crisis, work was restricted, and sometimes sporadic. My lifeline was and is medical assistance. That is now being taken away from me. My eligibility is being denied because I chose to work and earned an amount which exceeded the welfare allotment.

Patricia William of Applegate, Oregon, described the fate of an uninsured family whose son was diagnosed with cancer.

> Ryan's treatment utilized 23 doctors and three hospitals, for a total cost of over $140,000. Ryan died three months after the cancer was diagnosed, but the family was left with the debt and lost the family business and other property. This happened while the family was going through the trauma of losing their son. The family saved their home only because twenty of the creditors agreed to forego their debts.

7.3.2 The costs of care which no one covers

Even those with access to care and insurance coverage find that cancer treatment introduces substantial expenses they cannot afford. Insurance premiums and deductibles, and costs for outpatient medicines and medical supplies are among the healthcare costs which are typically unreimbursed.

Janice Raines of Tahlequah, Oklahoma, was able to get assistance to pay for two months of chemotherapy.

> The third time for the treatments I told the doctor I could no longer afford to come up with the money for the medicine. One prescription is $88, one is $68. I cannot buy a postage stamp and they expect me to pay this much.

The costs of time off from work, travel for treatment, child care and other support services are added to costs of unreimbursed medical expenses. Linda Squire of Hemet, California had a daughter who died of cancer.

> It isn't just the medical expenses. It includes all the gasoline for visits to and from the hospital and doctors' offices, insurance companies, Medi-cal and SSI offices and to pick up supplies. The cost of child care and a competent care taker for the patient. Then there is the cost of supplies not covered by insurance such as tape, gauze, Q-tips, etc. The phone bill becomes outrageous . . .

Things which many Americans take for granted, like transportation to health facilities, are unavailable to poor people and serve as additional barriers to access. Many people testified about delaying diagnosis or treatment because they could not afford to pay for gas, to rent a car or ride a bus. The problem is particularly acute for people living in rural areas who must often travel long distances to find appropriate care.

S. Kevin Howlett, a health educator with the Confederated Salish and Kootenai Tribal Health Department, described the choices made by Indians who often must travel long distances to regional cancer treatment centers. "The inconvenience and perseverance required to travel is often times not worth it. They tell me, 'We aren't going to make it anyway.'"

Barbara Johnstone traveled 13 hours on a bus from her home in Aspen, Colorado to Denver to receive treatment for breast cancer.

> I'd be on a bus with millions of people and cigarette smoke and I would be absolutely hysterical and so sick by the time I got there for treatment . . . There were so many times I just didn't want to go on and try any more . . . Instead of battling the disease, I'm battling the whole system trying to figure out what I can do.

Ms. Johnstone, who lost her job and her home during cancer treatment, has moved to Grand Junction, Colorado to be closer to care.

Transportation is not covered by public or private insurance nor is the cost of temporary housing for patients and family members who must travel long distances for care. Such costs can be particularly substantial for cancer patients undergoing daily radiation therapy.

7.3.3 Finding a reason to survive

With no job, and no money to pay for anything but medical bills, even poor people who survive cancer treatment find little to live for.

Theresa Hicks from Upper Marlboro, Maryland, put it well. "You go through so, so much when you live through cancer treatments," she told the panel, "you struggle for your life and then you make it and of course you are ecstatic that you're still alive . . . but the quality of life that you have to live when you are financially strapped almost makes you wish that you hadn't."

For some poor patients, the sacrifices they are asked to make to pay for care are simply too much. Forced to choose between living in despair or dying in dignity, they often accept the latter. Esther Lefever, a community activist in the Cabbagetown area of Atlanta, Georgia, told the story of one poor white woman she knew.

> One woman whose insurance ran out was told to apply for Medicaid. She realized this would mean she had to take a lien on her house. She told them she wanted to leave the house to her children free and clear and she would rather die than do that. Two months later she was dead.

There remains a strong stigma against public assistance programs among many poor and near poor people. Some people who are eligible for Medicaid, for example, will not apply for benefits because they are too proud.

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7.4 Cancer education and outreach efforts are insensitive and irrelevant to many poor people.

Americans can take steps to reduce their cancer risk by avoiding exposure to carcinogens, eating right, knowing cancer warning signs and getting cancer-related check-ups. While awareness of these steps to prevent cancer is increasing, testimony revealed important messages are not getting through to the people with the greatest need to hear them.

There are many reasons for this education gap. Professionals and disadvantaged people spoke of the need for more education programs which are culturally relevant to various segments of poor populations and appropriate for people with little formal education. In addition, they stressed the importance of involving poor people themselves in outreach programs focused on prevention, early detection, and cancer recovery.

7.4.1 Reaching into poor communities

Cancer education efforts have not penetrated poor communities and tapped into information networks which many poor people rely upon, such as churches, schools, community groups and family members. Few volunteers involved in cancer education understand and relate to the problems of the poor.

Sister Thea Bowman, a cancer survivor who works with disadvantaged people in Mississippi, described the problems poor patients have in understanding their disease and their treatment options.

> Often, the person who is poor lacks education, and they don't understand the language. They don't understand medical terminology. They sometimes don't understand the basic body parts. They've been told, but they do not understand.

Like other testifiers, Sister Thea spoke passionately of the need for volunteers who are sensitive to the needs of poor patients.

> If outreach workers are middle class, they need to understand what it means to be poor . . . poor people's attitudes, some of their problems, some of the special needs of the poor. A different kind of listening skill is required.

In many poor communities, there is a strong distrust of people from outside the community. "The distrust is real," said Dr. David Allen, director of Health for the Louisville and Jefferson County Board of Health in Louisville, Kentucky. "There are barriers to a person from the outside."

Dr. Allen recommended recruiting volunteers from poor communities. "In every community you'll find a few people who are potentially spokespersons for the community . . . if you can get them . . . you can overcome some of these trust barriers."

Judith Hadley, a breast cancer patient from Portland, Oregon, described how a volunteer might have been able to help her cope.

> I needed to see someone who had lived through it. I didn't care about the words. I needed to see someone standing there. And they said . . . they couldn't find anybody who was like me.

7.4.2 Making cancer education compelling

Few existing cancer education materials feature minorities in visuals and few are available in languages other than English. The result: many minorities believe cancer is not a disease likely to affect them. "It looks like black people don't suffer from cancer," said Dr. Margie Cook of the Coalition of Black Nurses. "Only one poster I've seen has a black person on it."

"Indian people do not see cancer as an Indian disease," said Jean Davis, a nurse educator at W.W. Hastings Indian Hospital in Tahlequah, Oklahoma. "If you can give them a piece of paper with a picture of an Indian on it, that is theirs. Whereas if it's a white man, that's a white man's disease."

The need for culturally sensitive materials applies to poor whites as well as to minority audiences; testifiers illustrated that poor whites are often overlooked because program planners often assume that they are reached through materials targeted to the general population. As a result, there is a lack of outreach into poor white communities and too few education materials suited to low reading levels.

Many testifiers pointed to the inappropriateness of printed materials in general, since many poor people are illiterate or have very low literacy and will not pay attention to pamphlets and brochures.

Poverty itself is a strong barrier to education about cancer. Health prevention messages, which focus on long-term risk reduction seem irrelevant to people who are living day to day. Anna Walton, an oncology clinical nurse specialist and director of a hospice in Somerset, Kentucky, described an experience she had when she first started working in this area.

> I ran into a family who I was explaining good nutrition to and it came down to the fact that I had to say, "You need to feed your family." The woman was not aware that her kids had to eat every day.

7.4.3 Trading small pleasures for better health

Many poor people say they get special enjoyment from small pleasures, like cigarettes or junk foods which they know contribute to increased cancer risk. As Susan Walker, a visiting nurse from Maryland put it: "Unless people feel that they have an economic future and a hope to better themselves, I think I will continue to find people turning to cigarettes and alcohol to deal with their anxiety, anesthetize their pain and give them immediate pleasure."

Janet Nutt of Des Moines, Iowa, told of her efforts to warn her illiterate brother about the risk of smoking.

> Jerry was a heavy smoker. Many times I encouraged him to quit, but he would say, "Janet, they are all I really have in my life. "When I would explain to him the dangers of smoking, he still had those feelings, "It will never happen to me."

Jerry died of lung cancer in 1988 at age 45. By the time he was diagnosed, little could be done.

There are additional barriers to education about cancer in communities which depend on tobacco or other cancer-causing agents for their livelihood. "Our source of income is killing us," said Michelle Logsdon, from a tobacco growing community in Kentucky.

Testimony also acknowledged that knowledge is only one influence on behavior. In order to break through to this audience, educators must consider the context in which the message is delivered. Rebecca Ramos, director of the Hispanic Health Promotion Project of the Paso del Norte Area Health Education Center in El Paso, put it well.

> Health habits are tightly woven into the fabric of a person's entire life . . . his/her emotional needs, self-image, cultural values, and beliefs, social networks, and changing opinions about what is chic, sophisticated and macho.

To be effective, testifiers established, education efforts must appeal to existing beliefs and values.

7.5 Fatalism about cancer prevails among the poor and prevents them from gaining quality healthcare.

The consequence of inadequate cancer education among the poor is that misperceptions about the disease and its prevention, detection and treatment prevail among this group. At the core of the problem is a belief that a diagnosis of cancer is a death sentence. A sentence which many are willing to accept as their fate.

Joan Ross, executive director of the Southwestern Community Action Council in Huntington, West Virginia, described how people in this Appalachian community react to the subject of cancer. "People avert their heads, they lower their voices, they don't want to discuss something that to them is always terminal," she said. "It is a sentence to die."

Michelle Logsdon, a receptionist from Russell Springs, Kentucky, has six family members who have had various kinds of cancer. In seeing how friends and family members have reacted to the disease, she has had first-hand exposure to the fatalism which stops many from seeking help.

> Today, most of the people I know are of the opinion that there are no odds against cancer, only a funeral. They do not really realize that cancer can be cured if detected early enough; and they are not made aware that there is hope. Hope of surviving, and hope that, even though the treatment can be painful, there is survival.

7.5.1 Accepting a life sentence

This sense of fatalism about cancer also affects poor people's attitude towards prevention and early detection. Many report they do not seek early diagnosis because they are frightened of learning they have a serious illness. Others see cancer as a disease that will affect someone else -- not them. They think if they ignore warning signs, they might go away.

Martha Cromer is a Spanish-speaking Hispanic woman who testified with the help of a translator. She spoke of her reluctance to see a doctor about a birthmark which was troubling her. As the translator described, "She had known that this thing was growing and it looked strange but she was afraid to look for trouble. She was having a lot of problems already; she didn't want to add to it by looking for them."

Many poor people who presented testimony were deeply religious and felt that they had cancer because it was "God's will." Religious belief led some to conclude that they should let the disease run its course without treatment.

Misperceptions prevail, in part, due to weaknesses in cancer education and outreach efforts. But they also prevail because the experiences of poor cancer patients, who often receive medical attention at great cost and with little positive health effect, reinforce perceptions that little can be done to help those who have this disease. Mary Gomez Lona is director of the Richard Cabot Clinic in Kansas City, Missouri.

> There's a fatalistic attitude, but there's a reason for that attitude . . . their realities are that people do die from cancers. Their realities are that if you don't have money, you're not going to get treated and you are gonna die.

7.5.2 Feeling the pain of ignorance

Poor cancer patients are often placed in the uncomfortable position of trying to make decisions about their personal health based on conflicting information from health providers and from their families and friends.

Cancer myths create additional burdens for poor patients who are shunned by their coworkers, their families and friends. Fatima Perez, who moved to New Jersey from Santo Domingo in 1988, described through a translator how she was treated by her own family members who thought her skin cancer was contagious. "She got beat up and put outside because they don't want her near the baby," the translator explained. They believe "the baby can catch what Fatima has."

Recovering cancer patients may face job discrimination based on misperceptions about cancer. Jose Gardea is an electrician who received treatment for a brain cancer and sought to return to work with contractors who had employed him in the past.

> You tell these people you have cancer and they think it's poison. They get scared of you. I call my friends "Hey, at least put me to work once a week, twice a week, just to survive," they won't do it. They just close the doors on you.

With little knowledge about cancer, poor patients are also left without the means to influence their own treatment. After successfully fighting the system and getting some kind of care, some look back and know it could have been easier, it could have been better.

"If I knew what I know now I could have questioned their diagnosis," said Shirley Laos, a cancer patient from Trinidad, California. "If I had known, had more information, I could have gotten to the specialist two to three years earlier than I did, and it probably would have made a difference."

7.5.3 Giving patients a reason to hope

An important challenge in overcoming fatalism about cancer is helping poor cancer patients to find the will to survive. Marilyn Johnson is Director of Action on Minority Health, a project of the Center for Science in the Public Interest, based in Washington, D.C. She pointed out the importance of using education efforts to help give poor people some hope.

> Before any type of education can take place, minorities have got to be made to feel that they matter, that they are more than a statistic, a negative being. Messages being conveyed through the media have got to be tempered with some positive messages so that people will think they have a reason to live and that life is worth saving.

"People need to feel good about themselves and their ability to make changes within their own lives," agreed Ngina Lithcott, assistant professor of community health and preventive medicine at Morehouse School of Medicine in Atlanta, Georgia. She stressed that poor people need to believe it is in their power to do something about cancer. "People with low self-esteem, which include the poor, especially need the sense of empowerment," she said.

Testifiers recommended involving poor people, especially cancer survivors, in community education and support programs to help others take control of their disease and its treatment.

APPENDIX A

TESTIFIER PROFILES

ATLANTA HEARING
TESTIFIER PROFILES

Scheduled Testimony

Bernellyn Carey, Chairperson, Public Education Committee, Maryland Division, American Cancer Society, Baltimore, Maryland. Ms. Carey presented testimony on behalf of the Atlanta Regional Hearing Committee.

Joan Ross, Executive Director, South Western Community Action Council, Huntington, West Virginia. Ms. Ross has worked with the extremely poor communities in Appalachia for many years. She provided insights into the needs of rural isolated communities where people have to travel as far as 150 miles to get healthcare. (*)

Albert Lopez, M.D., Assistant Professor of Medicine, University of Puerto Rico, Puerto Rico. Dr. Lopez, a private practice physician, is an oncologist/hematologist. He has been an ACS volunteer for five years and is currently president of the ACS Puerto Rico Division. (*)

Jacqueline Simmons, M.D., Medical Director, North Dade Health Center, Miami, Florida. In 1987, Dr. Simmons was involved in planning the Early Cancer Detection Screening Program which identifies medically underserved minority women and men at risk for developing cancer. The first phase of the program is centered around screening women by means of a traveling mammogram van. (*)

Janelle Goetcheus, M.D., Medical Director, Health Care for the Homeless Project, Washington, DC. Dr. Goetcheus lives at Christ House, a facility where 34 homeless persons who are ill stay during their period of recovery. She often finds persons in shelters or on the streets suffering from cancer in its advanced stages. (*)

Edith Jones, Director, Neighborhood Services, S.T.O.P. Organization, Norfolk, Virginia. S.T.O.P Organization is a Community Action Agency serving the Norfolk area. Ms. Jones has been involved for many years in obtaining a variety of services for the economically disadvantaged, including food, housing and health care services. (*)

Boise Jackson, Gainesville, Florida. Mr. Jackson, who is black, was diagnosed with lung cancer. Though in constant pain, he voluntarily gave up a lifetime of disability income to go back to work, doing maintenance and custodial work. Mr. Jackson makes payments on his outstanding medical bills whenever he can, but has a hard time paying for his expensive -- and uncovered -- medication.

(*) -- Also submitted written testimony.

Cassandra Middleton, John's Island, South Carolina. Ms. Middleton, who is black, was diagnosed with osteosarcoma in 1985 and was treated at the National Institutes of Health in Maryland before moving to South Carolina. She is a single, unemployed mother of two children.

Alzada Guice, Atlanta, Georgia. Ms. Guice, who is black, was diagnosed with lymphona cancer. Although there was a difficulty in identifying her cancer, Ms. Guice has received chemotherapy and radiation treatments and now is a leader in cancer support groups at Grady Hospital in Atlanta. (*)

Carol and Okie Mayle, Phillippi, West Virginia. Mr. Mayle, who is white, has had a personal experience with lung, liver and bone marrow cancer. Despite "warnings" from friends about the bad effects of chemotherapy, he received it and his cancer is now in remission. At the time of his diagnoses in June, 1988, he was given less than two weeks to live.

Cathy Bolia, Atlanta, Georgia. A teacher's aide with the Atlanta Public School System, Ms. Bolia, who is Vietnamese, was diagnosed with late-stage colon cancer. She has expressed that she comes from a society in which cancer -- in any form -- is a misunderstood illness. It is believed cancer is curable if one can find a good doctor.

Theresa Hicks, Upper Marlboro, Maryland. Ms. Hicks, who is white, was diagnosed in 1972 (age 15) with bone marrow cancer in her left leg. After radiation treatments at NIH, her cancer is in remission. Last year, Ms. Hicks underwent brain surgery for a noncancerous tumor possibly brought on by her radiation treatments. After a difficult childhood, she is divorced with two children and, at the time of testimony, was facing foreclosure of her house.

May Linda Heyward, Health Educator, East Midlands Health District, Columbia, South Carolina. Ms. Heyward is an active and founding member of the South Carolina Coalition for Public Health, which advocates improved health among minority populations. Through her work she has worked on health intervention programs ranging from chronic disease and AIDS to teen pregnancy, sex education and family planning. (*)

Marie Lauria, Medical Social Worker affiliated with North Carolina Memorial Hospital, Chapel Hill, North Carolina. Ms. Lauria has been an American Cancer Society volunteer for 15 years. She has been committed to helping children with cancer and their families. (*)

Esther Lefever, Cabbagetown, Atlanta, Georgia. Ms. Lefever has worked for 20 years in the neighborhood center in the Cabbage Town community, helping to provide a variety of services to economically disadvantaged people. Personally, she has been cured of breast cancer. (*)

Elizabeth Ward, Assistant to the Mayor's Representative in Baltimore, Maryland. Ms. Ward is responsible for directing residents to social and health services in the community. She has participated in community high blood pressure and cancer programs, and also runs a soup kitchen. (*)

Open Testimony

Amelia Williams, Social Worker, Radiation Therapy Department, Grady Hospital, Atlanta, Georgia. (*)

Judy Bradley, RN, Nurse Consultant, Columbia, South Carolina.(*)

Ngina Lithcott, Assistant Professor of Community Health and Preventive Medicine and Director of the Health Promotion Resource Center, Morehouse School of Medicine, Atlanta, Georgia.

Amelia Broussard, Director, Atlanta Community Health Program for the Homeless, Atlanta, Georgia. (*)

Frank Rumph, MD, Director of Community Health, Public Health Department of Human Resources, Atlanta, Georgia.

JACKSON HEARING
TESTIFIER PROFILES

Scheduled Testimony

Anna Walton, Director, Somerset Hospice, Somerset, Kentucky. In rural Appalachia, Ms. Walton sees many people who have never been to a doctor. Pulaski County (where Somerset is located) has one of the highest, if not the highest illiteracy rate in the nation. (*)

JoAnn Calhoun, Somerset, Kentucky. Ms. Calhoun's husband, Roy, who is white, sought treatment for what he thought was pneumonia in April of 1989 and was diagnosed with terminal lung cancer. Ms. Calhoun comes from a very poor family with a history of cancer. (*)

Sandral Hullett-Robertson, M.D., Director, West Alabama Health Service, Eutaw, Alabama. Three of the counties that Dr. Hullett-Robertson's community health center serves fall within the ten poorest per capita income counties in the nation. She also is a Community Task Force Member.

John Lowe, Dr.P.H., Associate Professor and Scientist, Comprehensive Cancer Center, University of Alabama at Birmingham, Birmingham, Alabama. Through past work and as the principal investigator of a grant to look at dissemination of cancer education to the economically disadvantaged, Dr. Lowe understands the issues surrounding cancer care and the disadvantaged. (*)

Mona Arreola, Ph.D., Assistant Director, Cancer Center of the University of Tennessee at Memphis, Memphis, Tennessee. Dr. Arreola has conducted research on the special problem of late-stage diagnosis among rural black populations, and on the disparity of cost between public and private hospital care. She has prepared a proposal for a portable mammogram screening project. (*)

Louis Bernard, M.D., Dean, School of Medicine, Meharry Medical College, Nashville, Tennessee, Dr. Bernard presented testimony on behalf of the Jackson Regional Hearing Committee. He has been an American Cancer Society volunteer for more than 30 years and is currently the Chairman of the ACS Board of Directors in Tennessee.

Judy Barnes, Belzoni, Mississippi. Ms. Barnes, who is white, has been diagnosed with breast cancer. Both she and her family are uninsured because they can not afford health care insurance and have been denied by Medicaid. (*)

Michelle Logsdon, Russell Springs, Kentucky. Ms. Logsdon, who is white, is a receptionist for the Lake Cumberland Area Development District in Russell Springs. She speaks from close personal experience with cancer -- six members of her family have been stricken with it; her father and grandmother still live with the disease. She understands the attitudes of her community as they relate to cancer.

Fannie Langford, Memphis, Tennessee. Ms. Langford, who is black, was diagnosed with cancer of the larynx and had a larengectomy. She had been a smoker for 32 years. Ms. Langford did not and does not have any insurance. (*)

Lillie Shaw, Memphis, Tennessee. Ms. Shaw, who is black, has a family history of cancer, was diagnosed with breast cancer. Though she knew she had a lump and had insurance, she postponed treatment to take care of her ailing sister.

Sister Thea Bowman, Jackson, Mississippi. Sister Thea, who is black, has breast cancer. She was a Courage Award winner and has made significant contributions to her local community. She spoke about the need for cultural sensitivity when dealing with cancer patients.

Gordon Bonnyman, Attorney, Legal Services of Middle Tennessee, Nashville, Tennessee. Legal Services is a legal aid program that serves the poor through helping them obtain health coverage and disability -- SSI, Medicaid and Medicare. Mr. Bonnyman is also the chairman of the American Cancer Society Public Issues Committee for the Tennessee Division. (*)

L.C. Dorsey, Ph.D., Director, Delta Health Center, Mound Bayou, Mississippi. The Delta area of Mississippi and Mound Bayou in particular is one of the highest poverty areas in the state of Mississippi. Dr. Dorsey has studied poverty in the area and has worked extensively with the residents to help them receive a variety of health services. (*)

Claude Fox, M.D., State Health Officer, for the Alabama Department of Public Health, Montgomery, Alabama. With a combined dedication to public health and pediatrics, Dr. Fox has been involved in many areas relevant to health care for the economically disadvantaged, including infant mortality. (*)

Scott Morris, M.D., Director, Church Health Center, Memphis, Tennessee. Dr. Morris provides primary health care to indigent members of the Memphis community.

David Allen, M.D., Director of Health, Louisville and Jefferson County Board of Health, Louisville, Kentucky. In this position and as a member of a local Committee on the Poor, Dr. Allen is keenly aware of issues facing the poor in Kentucky. (*)

Jim McVay, Director of the Division of Health Promotion and Disease Prevention of the Alabama Department of Health, Montgomery, Alabama. Mr. McVay discussed the medicaid Program in Alabama as well as state legislation regarding cancer.

Open Testimony

Mardean Scott, Gloster, Mississippi. Ms. Scott, who is black, spoke about her family's experiences with cancer. She has been diagnosed with colon cancer.

Frank McCune, MD, private practice physician, Jackson, Mississippi.

Randy Caperton, Director of Chronic Disease Programs for Mississippi State Department of Health, Jackson, Mississippi.

Ken McCullough, PhD, Executive Director of the Adult and Community Education for Tennessee and Chairman, Graduate Program, University of Tennessee in Knoxville, Tennessee.

NEWARK HEARING
TESTIFIER PROFILES

Scheduled Testimony

Emigdia Mendez-Johnson, New London, Connecticut, Ms. Mendez-Johnson volunteers for the American Cancer Society and works with indigent Hispanics.

Adewale Troutman, MD, Medical Director, Newark Department of Health and Human Services, Newark, New Jersey. Dr. Troutman addressed the need for nontraditional and multidisciplinary approaches to the health care needs of the economically disadvantaged with a focus on primary prevention and community inclusion. (*)

Steven Edelman, MD, Director, Expanded Health Services, Lawrence and Memorial Hospital, New London, Connecticut. Expanded Health Services is a clinic where people are charged for service based on their salary. Dr. Edelman has worked with the poor around the world and recently ran a program to give free mammograms. (*)

John Dodds, Director, Philadelphia Unemployment Project, Philadelphia, Pennsylvania. Mr. Dodds has worked in health care for the poor for over 15 years and has worked in assisting people who have been denied health care services. (*)

Alejita Ortiz, Coordinator for Hispanic Outreach, Cancer Care, Inc., New York City, New York. Cancer Care is an organization which provides free counseling and community education programs. (*)

Virginia Peters, Philadelphia, Pennsylvania. Ms. Peters' husband, Charlie, who was white, died from cancer. She feels that he was treated "like a freak" during his hospital stay. He was left for days without health care while in the hospital, which resulted in bed sores and pneumonia. Mr. Peters had healthpass insurance (one must be on Welfare to receive it.) (*)

Fatima Perez, New London, Connecticut. Ms. Perez moved to this country about one year ago from Santo Domingo. Doctors in Santo Domingo had diagnosed her with skin cancer and told her to move to the U.S. They said she would die there in the hot sun. Ms. Perez is also blind and suffers from Lupus. She has been humiliated and ostracized by her family; they think she's contagious and will infect their new baby.

Robert Lee, Burlington, New Jersey. Mr. Lee's wife, who was black, passed away on May 7, 1989, from breast cancer. She had a benign tumor removed on September 2, 1988. One month later when she went for a checkup, the doctors found the cancer had spread. The Lee's insurance was terminated because the insurance company said they never received his checks although he sent the payments. He is unsure of the exact amount that he owes the hospital; he has spent most of his retirement money on those bills.

Adelaide Kaplan, Hempstead, New York. Ms. Kaplan, who is white, was diagnosed in 1963 with reticulum cell sarcoma and recently with DHL. Her treatment and costs cause her problems which still exist today. She wants to work, but will lose her Medicaid benefits if she does. (*)

Robert McElligott, Warwick, Rhode Island. Mr. McElligott, who is white, was diagnosed with Stage 4 cancer of the tongue when he was being treated for injuries sustained in a car accident. He delayed seeking treatment because he was uninsured. He is currently in debt for approximately $30,000.

Marianna Herrera, Washington, DC. Ms. Herrera's mother, who is Hispanic, has been diagnosed with cancer. Ms. Herrera spoke about the cultural problems as well as the financial problems they faced in seeking care for her. Her mother is also having a difficult time paying for and securing home care.

Edna Fairbanks-Williams, Montpelier, Vermont. Ms. Fairbanks-Williams, who is white, had breast cancer and risks becoming uninsured when her husband's mill closes later in 1989.

Michelle Falter, Providence, Rhode Island. Ms. Falter is a single white mother of three children, one of whom has been diagnosed with leukemia. While she is covered by Medicaid now, she is still trying to settle bills from 1987.

Tom Harding, Farmington, New Hampshire. Mr. Harding, a white father of 11, has been diagnosed with cancer of the spine. He has been in a constant fight to get Social Security and has expressed deep concern about his family's well-being. He feels he's been stripped of his dignity through this ordeal. (*)

Barbara Oldwine, Binghamton, New York. Ms. Oldwine testified on behalf of the Newark Regional Hearing Committee. Ms. Oldwine has been a health and housing advocate for disadvantaged families, women, and children. She has been a social worker and member of the Board of Directors of American Cancer Society, New York State Division.

Susan Constantine, Social Worker in Radiation Therapy, Rhode Island Hospital, Providence, Rhode Island. Ms. Constantine is a social worker with the Rhode Island Hospital, Department of Social Work, which is located in a low-income area.

Kathleen B. Rogers, Clinical Director of Oncology Services, Lakes Region General Hospital, Laconia, New Hampshire. One area of Ms. Rogers' work and research is the cancer prevention/early detection needs of the elderly. (*)

Selma Morris, Nurse Educator, Boston University School of Health, Boston, Massachusetts. Ms. Morris is a nurse educator with Boston University School of Health. She has chaired a multi-cultured committee for the American Cancer Society.

Alan Hark, Staff Paralegal, Vermont Legal Aid, Inc., Montpelier, Vermont. Vermont Legal Aid is a civil poverty law practice for the state. Mr. Hark is also Chairman of the Board for the State Health Planning Agency.

Annette Jolles, Clinical Social Worker, Oncology Program, Washington Hospital Center, Washington, DC. The District of Columbia has the poorest statistics for cancer survival in the United States. Ms. Jolles' clinic offers low-cost health care services. (*)

Open Testimony

Lois Bronze, Westchester County, New York. Ms. Bronze works with the economically disadvantaged.

Stacy Stringer, Newark Beth Israel Medical Center, Newark, New Jersey.

John Slade, MD, FACP, Chairman, Commission on Smoking Oregon Health Commission of the State Health Department, New Jersey.(*)

Francine Kinard, Paraprofessional Staff, American Cancer Society, Philadelphia, Pennsylvania.

ST. LOUIS HEARING
TESTIFIER PROFILES

Scheduled Testimony

Samuel U. Rodgers, MD, MPH, Executive Director, Samuel U. Rodgers Community Health Center, Kansas City, Missouri. Dr. Rodgers is a recognized national authority on health care and the poor. He founded the first inner-city health clinic 21 years ago and remains its only director to date, and he was the first black OB/GYN in Kansas City. (*)

David Ansell, MD, Director of the Breast and Cervical Cancer Screening Program, Cook County Hospital, Chicago, Illinois. The General Medicine Clinic sees approximately 68,000 patients per year. Approximately 50 to 60 percent of the 1.5 million medically indigent in Illinois live in Cook County. (*)

Jesse Sharpe, Director of Community Services for Family Service, Omaha, Nebraska. Mr. Sharpe has been instrumental with the American Cancer Society's outreach to the economically disadvantaged North Omaha community since the inception of the program. (*)

Pati Maier, State WIC (Women, Infants and Children) Administrator, Minnesota Department of Health, Minneapolis, Minnesota. Under Ms. Maier's direction, a marketing survey was implemented to determine the needs of the "working poor" who access county WIC programs. (*)

Margaret McClusky, RN, Director of Oncology Services, Home Care Providers, Chicago, Illinois. Ms. McClusky testifed on behalf of the St. Louis Regional Hearing Committee. She is certified nationally in oncology and certified in the early detection and prevention of cancer by the University of Texas at M.D. Anderson Hospital and Tumor Institute in Houston.

Martha Cromer, Kansas City, Missouri. Ms. Cromer, who is Mexican, was diagnosed with melanomas all over her body. She postponed treatment until she could get on Medicaid and because some of the melanomas were on private parts of her body. Her last name in Spanish means "birthmark" and so Ms. Cromer accepted the marks on her body as her destiny.

Mary Gamez Lona, Director of the Richard Cabot Clinic, Kansas City, Missouri. The Richard Cabot Clinic is a non-profit family clinic for the medically indigent which has been in existence for more than 70 years. The clinic has a reputation for upholding the rights of the poor.

Dorothy Thompson, Canton, Ohio. Ms. Thompson, who is black, was diagnosed with breast cancer in 1982. She was aware of her symptoms for a year and a half before seeking treatment. Her first physician refused her chemotherapy because she was on welfare. (*)

Neva Phillips, Detroit, Michigan. Ms. Phillips, who is black, was diagnosed with breast cancer. Ms. Phillips lost her insurance when she quit her job in May of 1988 because of a discrimination case. She currently works part-time and cannot pay her bills. She never had a mammogram and thought for one year that the pain in her chest was heartburn.

Diana Metcalf, Fort Thompson, South Dakota. Ms. Metcalf, who is a Native American, has been diagnosed with breast cancer. The public health service offered to give her a free mammogram a year before she was diagnosed. Many women, including Ms. Metcalf, refused the free mammograms because, as she said, "Indians get embarrassed."

Joan Clemmons, St. Paul, Minnesota. Ms. Clemmons is a single white mother who was diagnosed six years ago with non-Hodgkins lymphona. She postponed treatment because she attributed her significant weight lose to the many hours she was working. Ms. Clemmons is only one of seven people her age in the country with this diagnosis. She has stated that "if you are going to get cancer, get a popular one; otherwise, nobody cares."

Dorothy Jones, Detroit, Michigan. Ms. Jones' daughter, Belinda Pettigore, who is black, was diagnosed with cancer. She often does not have the transportation to get the medicine she needs. Ms. Pettigore at one point was cut off for social services because she did not appear at the Department of Social Services for an appointment, even though she was in the hospital at the time. (*)

Marie Carter, Chicago, Illinois. Ms. Carter, who is black, was treated at Cook County Hospital for cancer and has subsequently become a patient advocate for breast cancer patients at the hospital.

Inez Black-Hawk, Mandaree, North Dakota. Ms. Black-Hawk has been diagnosed with stomach cancer. Some of her treatment is covered by Indian Health Services but she keeps getting bills from the hospital and doesn't know what to do with them. The local clinic doesn't stock her medicine, so she has to travel 170 miles to get chemotherapy and radiation. (*)

Mary McDaniels, St. Louis, Missouri. Ms. McDaniels, who is black, had a modified mastectomy about five years ago. She was partially covered by insurance, but was financially strained because of her out-of-pocket expenses. She postpones her bi-yearly checkups -- sometimes as much as 6 months or more -- because she can't afford the $300 charge. Ms. McDaniels currently does home health visits for other patients.

Ruby Hyram, Florissant, Missouri. Ms. Hyram, who is black, was diagnosed wtih breast cancer. She has had trouble with her Medicare coverage and premiums.

Tolly Estes, Crow Creek Indian Reservation, Fort Thompson, South Dakota. Mr. Estes works for an Episcopal church which works primarily with cancer victims and youth from the Sioux Indian tribe.

Carole Hutchings, Executive Director, Witwer Senior Center, Inc., Cedar Rapids, Iowa. Ms. Hutchings serves as vice-chair of one of 10 units selected to participate in the national Lane Adams grant award programming. As the vice-chair of the public education committee, she works to develop cancer awareness, detection and early treatment programming for the elderly and economically disadvantaged. (*)

Open Testimony

Theodora Bird-Bear, Indian Health Services Clinic, Fort Berthold Reservation, New Town, North Dakota.

Del Doss-Helmsley, Chairperson, Public Education Committee, Missouri Division, American Cancer Society, St. Louis, Missouri. (*)

Eva Bradley, Volunteer, American Cancer Society, Canton, Ohio.

EL PASO HEARING
TESTIFIER PROFILES

Scheduled Testimony

Dr. Lovell Jones, Staff Member, Department of Gynecology at M.D. Anderson, Houston, Texas. Dr. Jones testified on behalf of the El Paso Regional Hearing Committee.

Nicki Scott, Social Services, Southern Louisiana Medical Center (SLMC), Houma, Louisiana. SLMC is one of nine charity hospitals in the state. Ms. Scott is an environmental social worker.

Jean Davis, RD, Nurse Educator, W.W. Hastings Indian Hospital, Tahlequah, Oklahoma. Ms. Davis interviewed economically disadvantaged people from north and southeastern Oklahoma and addressed the results of these interviews in her testimony.

Selma Schwartz, New Orleans, Louisiana. Ms. Schwartz, who is white, has been diagnosed with breast cancer. She lives at the Salvation Army Ladies' Lodge. According to the physician who nominated her, Ms. Schwartz is "a good example of how the poor get jerked around."

Jose and Mrs. Gardea, El Paso, Texas. Mr. Gardea, who is Hispanic, was diagnosed with a malignant brain tumor. He has been unable to pay the medical bills because he doesn't have insurance or Medicaid. He has not gotten disability insurance because he was self-employed; his lack of income has caused financial hardship for his family.

Ms. Consuelo, El Paso, Texas. Ms. Consuelo, a Hispanic mother of 14, was diagnosed with uterine cancer. She owes more than $6,000 in medical bills, her husband is unemployed and she is at risk of losing her dwelling.

Juanita Coy, Weslaco, Texas. Ms. Coy, a Hispanic, was referred to health care providers ranging from private physicians to clinics to county agencies; no one would treat her for her breast lumps because she had no money. She does not seek follow-up care because she can not afford it. (*)

Jorine Combs, Oklahoma City, Oklahoma. Ms. Combs, a Native American, spoke about the experience her son had with acute leukemia and the barriers he faced in trying to get care from both the Indian and local health systems. Her son's wife could not even afford the gas to travel to visit him in the hospital.

Cassie Cradure, Sulphur, Louisiana. Ms. Cradure testifed on behalf of her sister, Virgie, who was white, and died of cancer in June of 1989. Vergie's bills are being paid by community bingo game donations; her daughters are working extra jobs to help pay the rest. (*)

Elvia Maisonet, El Paso, Texas. Ms. Maisonet, a Hispanic single mother of two, was diagnosed with uterine cancer five years ago. Her father died of cancer, and both suffered financial hardship because of the disease.

John and Rosemary Linder, El Dorado, Arkansas. Mr. Linder, who is white, suffers from chronic leukemia and is unable to work. He was self-employed but uninsured; the family lost their home and vehicles because of bills from his cancer. His wife has struggled to find a suitable donor and to raise the money to pay for a transplant. (*)

Janice Raines, Tahlequah, Oklahoma. Ms. Raines, who is white, was diagnosed with breast cancer. She lost her job and insurance and had to move in with relatives. She is facing lawsuits from the medical bills which she has been unable to pay.

Richard Ragan, Broken Arrow, Oklahoma. Mr. Ragan's 13-year-old daughter, Amy, who is white, has an abdominal tumor. Last year she was hospitalized 63 times. The family was evicted for falling behind in their rent because of medical bills; they face being evicted again.

Rowena Brown-Parker, Medical Social Worker, University of Arkansas for Medical Sciences, Little Rock, Arkansas. Ms. Parker has worked with cancer patients for more than six years. Many of her patients are residents of rural Arkansas who seek assistance from her facility due to socio-economic problems.

Lucille Hampton, Executive Director, Marlin Falls County Committee for Health and Community Development, Marlin, Texas. Ms. Hampton started this committee to address all the needs she saw in the community. She addressed the need to educate counselors from among target populations and to do more grassroot programs. Her brother and mother suffered from cancer.

Diane Mapes, Eastern Oklahoma Medical Center, Poteau, Oklahoma. Eastern Oklahoma Medical Center is a small, rural hospital which treats patients from a wide area who can't pay for health care. Ms. Mapes addressed the issues of illiteracy and poverty.

Guillermo Lopez, Social Worker, M.D. Anderson, Houston, Texas. Since 1980, Mr. Lopez has worked with Spanish-speaking, indigent cancer patients and their families. His work as a social worker includes not only assisting them in adjusting to the diagnosis and treatment of cancer, but facilitating the treatment with financial assistance for transportation, housing, meals and medical equipment.

Open Testimony

Robert Jackson, MD, LSU Medical School, Shreveport, Louisiana.

Mrs. Jose Salas, El Paso, Texas. Mrs. Salas, who is Hispanic, provided testimony about her husband experience with stomach cancer. (*)

Phyllis Armijo, Executive Director of Centro San Vincente, El Paso, Texas. (*)

Felipe Adame, Director of Social Services, Centro de Salud Familiar La Fe, El Paso, Texas.

Shirley Hutchins, Director of Nursing and Clinical services, El Paso County Health District, El Paso, Texas.

Donna Mahr, RN, EdD, Assistant Professor of Nursing and Allied Health, University of Texas at El Paso, El Paso, Texas. (*)

Angel Gonzalez, Planned Parenthood, El Paso, Texas.

Petra Maya, El Paso, Texas. Ms. Maya, who is Hispanic, provided testimony about her personal experience with uterine cancer.

Yvonne Flores, Trainer, DHS Department, El Paso, Texas.

SACRAMENTO HEARING
TESTIFIER PROFILES

Scheduled Testimony

Dr. Dileep Bal, Chief of the Chronic Diseases Branch, California Department of Health Services, Sacramento, California. Dr. Bal testified on behalf of the Sacramento Regional Hearing Committee. He is principal investigator on the National Cancer Institute's Grant entitled "Dietary and Cancer Control Objectives in California."

Dr. Brian Martin, Special Populations Division of the Cancer Research Center of Hawaii, Honolulu, Hawaii. A native Hawaiian, Dr. Martin is a computer specialist involved in research relating to native Hawaiians and cancer. He assists community-based organizations and the American Cancer Society with data collection and research.

Margaret Kanawaliwali Miyashiro, Molokai, Hawaii. Ms. Miyashiro is a native Hawaiian. She is a key agent for reaching grassroot communities as well as natural/cultural native Hawaiian healers.

Juanita Letson-Samuels, Trinidad, California. Ms. Letson-Samuels, a native American, testified on behalf of her daughter, Nola, who died of cancer in 1983. She addressed the problems of culturally sensitive medical care for the Indian population. Ms. Letson-Samuels now works as a hospice home patient care volunteer.

Shirley Laos, Trinidad, California. Ms. Laos, a native American, testified about her personal experience with cancer. Her emotional testimony provided insights into the information needs of the Indian extended family.

Jerome Simone, Executive Director of the United Indian Health Service, Inc., Trinidad, California. Mr. Simone testified on behalf of the Urock Indians who are members of the Trinidad Rancheria Reservation who have difficulty accessing health care.

Walt Seaver, Colusa, California. Mr. Seaver, who is white, is the father of an eight-year-old daughter, Emma, who has leukemia. The health insurance on Emma was cancelled and she is currently uninsured. Emma is in need of a transplant; their community, in a race against time, is trying to raise the funds for the operation.

Fannie Cotton, Richmond, California. Ms. Cotton, who is black, testified on behalf of her husband and daughter, who have been diagnosed with cancer. She describes their financial situation as "barely living." She is a board member of the West County Toxics Coalition, which fights against toxic waste disposal in their community.

Judith Hadley, Portland, Oregon. Ms. Hadley, who is white, was diagnosed with breast cancer. She has been "paying off" the bills incurred through her illness and treatment for years. She had suffered a heart attack at age 38 which complicated her insurance situation.

Eddie Cotter, Portland, Oregon. Ms. Cotter, who is black, was diagnosed with breast cancer. She is currently uninsured and is still paying for some of her oncology and chemotherapy treatments. Ms. Cotter's mother, aunt, brother and husband all died from cancer within a three-year period.

Christine Wilson, Portland, Oregon. Ms. Wilson, who is black, was diagnosed with breast cancer. She is covered by Medicare and welfare. She had chest pains for over a year which were misdiagnosed by doctors as arthritis or a heart attack. (*)

Dr. Neal Rendleman, Founder, Old Town Clinic, Portland, Oregon. Dr. Rendleman provided case studies of patients with cancer who had delayed treatment for a variety of reasons.

Claudia Anderson, Assistant Administrator, Fairbanks Home Health Care, Fairbanks, Alaska. Ms. Anderson works for the State of Alaska's Department of Health and Social Services. (*)

Linda Squier, Hemet, California. Ms. Squier, a who is white, testified on behalf of her daughter, who died of cancer in January 1989. The family knew that something was wrong with their baby when she was 6 months old, but "nobody would believe them." The family suffered financial and emotional hardships during two years of fighting for benefits before she died. (*)

Bonnie Nelson, Chugiak, Alaska. Ms. Nelson, who is white, has been diagnosed with Hodgkin's Disease, Lupus and rheumatoid arthritis. She believes she has been discriminated against by her insurer and employer, and has chosen "to be poor" in order to qualify for health benefits.

Margene Gordon, Sacramento, California. Ms. Gordon, who is black, was diagnosed with breast cancer. She lives on less that $400/month. She didn't know about mammograms prior to her illness. Ms. Gordon now reaches out to help other black women facing cancer.

Jayne Leet, Chief of Administration, Northwest Regional Primary Care Association, Seattle, Washington. Northwest Regional Primary Care Association is a privately-owned, federally-supported community health center that provides sliding scale health care to the disadvantaged. (*)

Nampet Panichpant-M, Program Manager, Health Care Agency of Orange County, Santa Ana, California. She is a leadership figure in Asian-Pacific health advocacy and has more than 20 years experience in international Asian health issues.

Jim Forde, Retired Director, San Diego County Health Agency, San Diego, California. Ms. Forde is a public health worker of national renown, especially in the area of smoking cessation. He addressed the irony of a political system that supports health threatening behaviors like smoking. (*)

Open Testimony

William Hayes, MD, Director, Oakland Cancer Control Program, Oakland, California.

Sylvia Jutila, Executive Director, Humbolt Del Norte Unit, American Cancer Society, Eureka, California.

Ahmadia Thomas, West County Toxics Coalition, Richmond, California.

Henry Clark, Director, West County Toxics Coalition, Richmond, California.

Rosella Moore, West County Toxics Coalition, Richmond, California.

Lucille Allen, West County Toxics Coalition, Richmond, California.

PHOENIX HEARING
TESTIFIER PROFILES

Scheduled Testimony

Dr. Jerry Olshan, Phoenix, Arizona. Dr. Olshan testified on behalf of the Phoenix Regional Hearing Committee. He is a former president of the Arizona Division of the American Cancer Society and serves as the medical delegate to the ACS National Board. Dr. Olshan has a private osteopathic practice in Phoenix, specializing in oncology.

Craig Skousen, Director, Social Services, Dixie Medical Center, St. George, Utah. Mr. Skousen provides psycho-social and financial counseling for patients in this small rural hospital. The government installed this regional cancer center here because of its proximity to the Nevada nuclear test site.

David Arguello, PhD., Professor of Health Policy, University of Utah, Salt Lake City, Utah. Dr. Arguello sits on the Executive Committee of the Utah Department of Health Ethnic Minority Health Committee.

Troy Olaveson, St. George, Utah. Mr. Olaveson, who is white, was diagnosed with lymphona. His first diagnosis was incorrect and his cancer spread by the time he was diagnosed. Mr. Olaveson was uninsured and had to quit working to qualify for Medicaid.

Emma Chee and Ella Morales (daughter), Phoenix, Arizona. Ms. Chee, a native American, was diagnosed with ovarian cancer. Her daughter took her in because she had to travel six hours to Phoenix for treatment. Most of her $298 monthly social security allowance is absorbed paying for basic necessities.

Barbara Johnstone, Grand Junction, Colorado. Ms. Johnstone, who is white, was diagnosed with breast and bone cancer. She had no insurance, lost her job and her home. She has fought incredible battles to attain assistance. (*)

Carol Westlake, Pavillion, Wyoming. Ms. Westlake's mother, who was white, died of cancer. Her mother chose to die at home because she did not have insurance and did not want to be a financial burden to her children.

Ellen and Jeff Robbins, Tucson, Arizona. Ms. Robbins, who is white, was diagnosed with breast cancer. She had no insurance at the time and she has had to battle collection agencies calling for money that the family does not have.

Richard and Lora Knoll, Boise, Idaho. Mr. Knoll, a white father of three children, was diagnosed with a brain tumor. He had quit his job as a restaurant manager to go college when he became ill. The financial burden and bureaucratic hoops they have gone through to get assistance are significant.

Margie Cook, PhD, Denver, Colorado. Dr. Cook has her master's degree in community health nursing and her PhD in psychology. She works with a coalition of black nurses who provide health education for the poor. She also trains students in the ways of community health care by taking them directly into the community.

Tamsen Bassford, MD, Director, Cancer Prevention Clinic at the University of Arizona Cancer Center, Tucson, Arizona. Dr. Bassford is a practicing family physician; a large portion of her patients are Hispanics who do not speak English and who "cycle" in and out of the medical system and have difficulty qualifying for assistance.

Emelin Martinez, RN, University of New Mexico Hospital, Albuquerque, New Mexico. Ms. Martinez specializes in gynecologic oncology. She is responsible for patient and family education, policy and procedure development and staff education. She has conducted some enlightening research on the poor in her area.

Rosella Anaya, Health Promotion Coordinator, Santa Fe County Senior Services Program, Santa Fe, New Mexico. Mrs. Anaya works directly with low-income, elderly Hispanic patients and understands the problems they face day-to day. (*)

Keith Sheets, Caldwell, Idaho. Mr. Sheets, who is white, was diagnosed with lymphoma when being treated for an automobile accident. He has been struggling with SSI, which says he can work, and his doctors, who say he can't. Because the health portion of his auto policy doesn't cover his cancer, and he had no personal health insurance, he currently owes approximately $30,000.

Peggy Sanderfur, Grand Junction, Colorado. Ms. Sanderfur's friend, Ralph Crosby, who was white, died of cancer; he delayed treatment because he thought he did not have the money to pay for care; he was eligible for veterans' benefits but did not know it.

Michael Mack, Phoenix, Arizona. Mr. Mack, a white father of three, has had several bouts of cancer. He has had difficulty with continuity of care which possibly resulted in a delay of diagnosis. His family is suffering financially. (*)

Lana Giron, Carson City, Nevada. Ms. Carson is a young Native American woman who is very active with her tribe. She works in a local clinic and is familiar with the barriers that Native Americans face.

Sandra Fairburn, Chief of Community Health Nursing, Nevada State Health Department, Reno, Nevada. Ms. Fairburn has practiced nursing for 25 years and understands the problems and barriers that patients in a rural community face.

Karl Evans, Doctor of Ministry, Director, English as a Second Language Program, Wesley Community Center, Phoenix, Arizona. Dr. Evans was involved in the study of 25 counties in the U.S. with the lowest per capita income in the country, and believes that regionalization of health services has hurt the poor.

Open Testimony

Vicky Hirschi, Phoenix, Arizona. Ms. Hirschi, a native American, testified on behalf of her mother who died of cancer.

Susan Marrington, Public Health Nurse, Riverton, Wyoming.

Greg Nugent, Phoenix, Arizona. Mr. Nugent, who is white, testified on behalf of his son who was diagnosed with a malignant tumor in his head.

Sharon Shumard, Tucson, Arizona. Ms. Shumard, who is white, testified on behalf of her son who was diagnosed with acute lymphocytic leukemia.

APPENDIX B

WRITTEN AND VIDEO TESTIMONY

ATLANTA WRITTEN TESTIMONY

R.C. Barksdale-Hall, Washington, DC.
Mr. Hall submitted testimony on behalf of several women in his family, including his mother, who had been diagnosed with breast cancer.

Wilda M. Ferguson, Commissioner, Virginia Department for the Aging, Richmond, Virginia.

Alan Mills, Vice President for Programs, West Virginia Division, Inc., American Cancer Society, Charleston, West Virginia.

Reginald L. Peniston, MD, College of Medicine, Howard University, Washington, DC.

Virginia Solberg, Executive Director, North Miami Foundation For Senior Citizens' Services, Inc., Miami, Florida.

Nancy L. Valentine, PhD, Extension Agent and Extension Associate Professor, West Virginia University Extension Service, Fairmont, West Virginia.

Susan A. Walker, Service Line Manager, Medical Social Services, Visiting Nurses Association, Hyattsville, Maryland.

JACKSON WRITTEN TESTIMONY

Gordon Bonnyman, Attorney, Legal Servies of Middle Tennessee, Nashville, Tennessee, submitted testimony on behalf of the following people:

Debra Bell, Dickson, Tennessee.
Ms. Bell was diagnosed with melanoma and an irregular pap smear.

Joe Allan Bennett, College Grove, Tennessee.
Mr. Bennett was diagnosed with lung cancer.

Fannie Briggs, Franklin, Kentucky.
Ms. Briggs was diagnosed with a gynecological tumor.

Sally Ruth Brown, McMinnville, Tennessee.
Ms. Brown was lost to follow-up for rectal bleeding because she couldn't pay for testing.

Jenny Cason, Nashville, Tennessee.
Ms. Cason was diagnosed with lymphoma.

Harold Chambers, Huntsville, Tennessee.
Mr. Chambers was diagnosed with non-Hodgkins lymphoma.

Penelope Dingus, Oak Ridge, Tennessee.
Ms. Dingus was diagnosed with chronic myelocytic leukemia.

Brenda B., Erwin, Tennessee.
Ms. B. was diagnosed with acute erythroleukemia leukemia.

Lillie May Kendall, Nashville, Tennessee.
Ms. Kendall was diagnosed with breast cancer.

Jeffery Long, Lafayette, Tennessee.
Mr. Long was diagnosed with a cystic tumor.

Lynnie Mabrey, Madison, Tennessee.
Ms. Mabrey was diagnosed with lung cancer.

Mary Mealor, Franklin, Tennessee.
Ms. Mealor was lost to follow-up for an emergency hysterectomy because she didn't have money to pay for services.

James Oliver, Lebanon, Tennessee.
Mr. Oliver was lost to follow-up for severe headaches because he didn't have money for tests.

Carlene Overton, Crofton, Kentucky.
Ms. Overton was diagnosed with lymphoma.

Loma Phillips, Lake City, Tennessee.
Ms. Phillips was diganosed with cancer of the esophagus.

Sonja Sanders, Moore County, Tennessee.
Ms. Sanders was diagnosed with cervical cancer.

Bill Schiffman, Sevierville, Tennessee.
Mr. Schiffman was diagnosed with cancer in his lungs, lymph system and abdomen.

Ellie A. Stafford, Whittleyville, Tennessee.
Ms. Stafford was diagnosed with colon cancer.

Mary Carpenter, Stanton, Kentucky.
Ms. Carpenter submitted testimony regarding her son who had been diagnosed with cancer.

Dennis A. Frate, PhD, Research Institute of Pharmaceutical Sciences, Rural Health Research Program, The University of Mississippi, Mississippi.

NEWARK WRITTEN TESTIMONY

Dael C. Cohen, MPH, Health Educator, Crozer-Chester Medical Center, Chester, Pennsylvania.

Michael R. Greenberg, Graduate Program in Public Health, Department of Urban Studies and Community Health, Rutgers University, New Brunswick, New Jersey.

Anita Kobre, Executive Director, Rockland County Unit, New York State Division, Inc., American Cancer Society, West Nyack, New York.

Bernice Kramer, MSW, Coordinator of Group Services, Adelphi University, Garden City, Long Island, New York.

Patricia Lynn Low, Epping, New Hampshire.
Ms. Low submitted testimony on behalf of her daughter, Michlynn, who died of brain cancer.

Geraldine Meyer, Castile, New York.
Ms. Meyer submitted testimony describing her personal experience with cancer.

Linda Rhodes, Commonwealth of Pennsylvania, Department of Aging, Harrisburg, Pennsylvania.

Mary Ann Romano, M.Ed., Philadelphia, PA.
Ms. Romano submitted testimony describing her personal experience with breast cancer.

ST. LOUIS WRITTEN TESTIMONY

Cecilia Fritsche, Milwaukee, Wisconsin.
Ms. Fritsche submitted testimony describing her personal experience with lymphona.

Juanita J. Helphrey, Executive Director, North Dakota Indian Affairs Commission, Bismarck, North Dakota.

Gwen Hickey, United Ostomy Association, Black Ostomate, Spokesperson, Waterloo, Iowa.

Jill Hoff, Milwaukee, Wisconsin.
Ms. Hoff submitted testimony describing her personal experience with chronic myelogenous leukemia.

Frank Kiener, ACSW, LSW, Broadlawns Medical Center, Des Moines, Iowa.

Janet Nutt, Des Moines, Iowa.
Ms. Nutt submitted testimony on behalf of her brother, Jerry, who died of lung cancer.

Rita Schreffler, MSSA, LSW, Oncology Social Worker, Social Service Department, Doctors Hospital, Massillon, Ohio.

Carolyn Smith, RN, Broadlawns Hospital, Des Moines, Iowa.

Eva Williams, ACSW, Assistant Director, Social Services Truman Medical Center - West, Kansas City, Missouri.

EL PASO WRITTEN TESTIMONY

Margaret Brown, Jacksonville, Arkansas.
Ms. Brown submitted testimony describing her personal experience with breast cancer.

Rose Collins, Little Rock, Arkansas.
Ms. Collins submitted testimony describing her personal experience with breast cancer.

Carmen Diaz de Leon, RN, BSN, Family Planning Services, Thomason Hospital, El Paso, Texas.

Sharon Fragoso, Harlingen, Texas.
Ms. Fragoso submitted testimony describing her personal experience with cancer.

Walter Ostergren, President/Chief Executive Officer, Life Planning Health Services, Dallas, Texas.

Jose Padron and Elizabeth Padron (daughter), Brownsville, Texas.
Mr. Padron and his daughter submitted testimony describing his personal experience with cancer.

Hazel Rowan, Bristow, Oklahoma.
Ms. Rowan submitted testimony regarding her three-year-old daughter's experience with cancer.

Berdia Williams, Lawton, Oklahoma.
Ms. Williams submitted testimony describing her personal experience with myeloma.

SACRAMENTO WRITTEN TESTIMONY

Doreen Ackerman, United Way of Columbia-Willamette, Vancouver, Oregon. Ms. Ackerman also submitted testimony on behalf of sixty people, some of which had cancer. These include:

Dorothy Conklin, Oregon (no city available).
Ms. Conklin died from liver, breast, and spine cancer.

Ryan Robertson, Applegate, Oregon.
Mr. Robertson died from cancer.

Veva Becker, Volunteer and Division Chairman, Alaska Division American Cancer Society, Fairbanks, AK.

Priscilla A. DeRemer, RN, NP, MS, Nurse Educator, OB/GYN Nurse Practitioner, San Francisco Community Clinic Consortium, San Francisco, California.

S. Kevin Howlett, Ed.M., Health Educator, Confederated Salish and Kootenai Tribal, Health Department of the Confederated Salish and Kootenai Tribes of the Flathead Reservation, Pablo, Montana.

Joyce Reeves, Laguna Niguel, California.
Ms. Reeves submitted testimony describing her personal experience with breast cancer.

Marie Schley Schirmer, Hemet, California.
Ms. Schirmer submitted testimony on behalf of her brother who died of lung and bone cancer.

Winston F. Wong, MS, MD, Asian Health Services, Oakland, California.

PHOENIX WRITTEN TESTIMONY

Bruce J. Arthur, Sr., Vanderwagen, New Mexico.
Mr. Arthur submitted testimony describing his personal experience with lung and kidney cancer.

Dianne Eblen, RN, Santa Fe, New Mexico.

Leanna Gaskins, Tucson, Arizona.
Ms. Gaskins submitted testimony regarding her personal experience with breast cancer.

Cathy Milton, RN, Oncology-Hematology, Maricopa Medical Center, Phoenix, Arizona.

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Sharon Terwedo, St. Luke's Hospital, Phoenix, Arizona.

LaRae Winn, Phoenix, Arizona.
Ms. Winn submitted testimony describing her personal experience with cancer.

NATIONAL ORGANIZATIONS' WRITTEN TESTIMONY

Linda King Aukett, Chair, Government Affairs Committee, United Ostomy Association, Inc., Westmont, New Jersey.

Marilyn L. Johnson, Director, Action on Minority Health, Center for Science in the Public Interest, Washington, DC.

National Digestive Diseases Advisory Board, Conference on Enterostomal Patient Education, Consensus Statement Summary, October 31 - November 1, 1988.

APPENDIX C

HEARING PANELISTS

PANEL MEMBERS
ACS REGIONAL HEARINGS ON CANCER AND THE POOR

Panel Chairs

Harold P. Freeman, M.D. ACS President. Dr. Freeman is former Chairman of the ACS National Advisory Committee on Cancer in the Socio-Economically Disadvantaged. He is Director of Surgery at Harlem Hospital Center, New York City and a Professor of Clinical Surgery, Columbia University College of Physicians and Surgeons, New York City.

Kathleen J. Horsch. Chairman, ACS National Board of Directors. Ms. Horsch is also President of D.O.V.E., a consulting firm for nonprofit organizations, and a faculty member of Metropolitan State University in Minneapolis, Minnesota.

American Cancer Society Panelists

Harold Amos, Ph.D. Dr. Amos is Chairman of the ACS Massachusetts Division Board of Directors. He is a Professor of Microbiology and Molecular Genetics, Emeritus, at Harvard Medical School, and has served as a member of the President's Cancer Panel and the National Cancer Advisory Board. Panel -- Newark.

Frederick Cohen, M.D. Dr. Cohen is a physician in the Oncology Department of Newark Beth Israel Medical Center. He is a member of ACS's National Service and Rehabilitation Committee. Panel -- Newark.

Jennie Cook. Ms. Cook, Co-chair of the Sacramento Regional Hearing Committee, is a delegate to the ACS National Board, Chairman of the ACS Public Education Subcommittee on Youth, and a member of the ACS Public Education Committee. She is a Past President of the Marin (California) Unit and Chairman of the California Division Public Education Committee. Panel -- Sacramento.

Thomas L. Dezelsky, Ph.D. Dr. Dezelsky is Vice Chairman of ACS's National Public Education Committee and Chairman of the Public Education Subcommittee on Cancer and the Poor. He is Chairman of the Public Education Committee, ACS Arizona Division, and a member of the ACS Arizona Division Board of Directors. He is an Associate Professor, Department of Exercise Science and Physical Education, Arizona State University. Panels -- St. Louis, Phoenix.

John William Eley, M.D. Dr. Eley is a Fellow in the Division of Hematology and Oncology, Department of Internal Medicine, Emory University and a Medical Epidemiologist, Georgia Center for Cancer Statistics, Emory University School of Medicine. He is a member of the Subcommittee on Anti-Smoking Policies in Hospitals and Industry, ACS Georgia Division. Panel -- Atlanta.

Irvin Fleming, M.D. Dr. Fleming is a Surgical Oncologist and Chief of Surgical Services at St. Jude Children's Hospital in Memphis, Tennessee. He is a member of the ACS National Board of Directors and is past President of the Tennessee Division. Panel -- Jackson.

Sue Frymark, R.N. Ms. Frymark, a Registered Nurse at Good Samaritan Hospital Cancer Rehabilitation Center in Oregon, is Director at Large, ACS Oregon Division Board of Directors. She is a member of ACS's National Nursing Advisory Committee and is a past Chairman of the ACS National Volunteer Development Faculty. Panel -- Sacramento.

Melba Hill, R.N. Ms. Hill, Co-chair of the Atlanta Regional Hearing Committee, is Director of Nursing, Fulton County Health Department, Atlanta, Georgia, and President of the Mid-Atlanta Unit, ACS Georgia Division. She is a past Clinical Program Coordinator of the Adolescent Health Program, Fulton County Health Department, Atlanta. Panel -- Atlanta.

Robert Johnson. Mr. Johnson, Chairman of the St. Louis Regional Hearing Committee, is a Hospital Administrator at St. Louis Regional Medical Center. Chairman, Regional Committee, ACS Hearings on Cancer and the Poor. Panel -- St. Louis.

John Kelly, Ph.D. Dr. Kelly, Chairman of the Jackson Regional Hearing Committee, is Director of the Department of the Navy's Regional Family Service Center in Mississippi. He is a member of ACS's National Faculty and is a past Chairman of the Board of Directors of the Mississippi Division. Panel -- Jackson.

Theodore C. Marrs, M.D. Dr. Marrs is a member of the ACS National Board of Directors and a past President of ACS's New Mexico Division. He is the Acting Executive Director of the Diagnostic Center for Handicapped Indian Children and a board member of the Indian Pueblo Cultural Center. He is a past Board President of the New Mexico Cancer Control Center. Panels -- El Paso, Phoenix.

Roger Meinershagen. Mr. Meinershagen, Chairman of the Phoenix Regional Hearing Committee, is a longtime volunteer with the Society. He is Chairman of the Arizona ACS's Interagency Committee and is a past Vice President of the Central Region in Arizona. Panel -- Phoenix.

Curtis James Mettlin, Ph.D. Dr. Mettlin, Chair of the ACS Committee on the Socioeconomically Disadvantaged, is Director of Cancer Control and Epidemiology, Chief of Epidemiologic Research, Roswell Park Memorial Institute, Buffalo, New York. He has been Director of Graduate Studies and Assistant Professor, Department of Sociology, State University of New York (Buffalo). Panels -- Jackson, St. Louis.

Eva Moya, M.S.W. Ms. Moya, representing the El Paso Regional Hearing Committee, is a social worker with Centro San Vicente, Daughters of Charity Community Services Agency in El Paso, Texas. Panel -- El Paso.

Nancy Reyes, R.N., M.S.W. Ms. Reyes, Chairman of the Newark Regional Hearing Committee, is a Public Health Consultant, Prevention and Control, AIDS Community Support Unit, East Orange, New Jersey. Panel -- Newark.

Robert J. Schweitzer, M.D. Dr. Schweitzer is a Vice President and President Elect of ACS. He is an Associate Clinical Professor of Surgery, University of California School of Medicine, San Francisco. He is a past Project Director, Breast Cancer Detection Demonstration Project and Breast Screening Long-Term Study, NCI, ACS. Panel -- Sacramento.

John R. Seffrin, Ph.D. Dr. Seffrin is Vice Chairman, ACS National Board of Directors and a Professor of Health Education, Chairman of the Department of Applied Health Sciences, Director of the Center for Health and Safety Studies, Indiana University. He is past Vice President, ACS Board of Directors, Chairman of the Board, ACS Indiana Division, and Chairman, ACS Public Education Committee. Panel -- Atlanta.

Dorothy Stake. Ms. Stake is a National Lay Delegate to the American Cancer Society. She is a member of ACS's National Public Information Committee and is President of the South Dakota Tri-Agency Coalition of Cancer, Heart and Lung Associations. She is a past Chairman of Board of Directors and Executive Committee, ACS South Dakota Division. Panel -- St. Louis.

Centers for Disease Control Panelists

Stephen B. Blount, M.D., M.P.H. Dr. Blount is Director of CDC's Office of Surveillance and Analysis, Center for Chronic Disease Prevention and Health Promotion. He is a past Director of Cancer Control Research, Michigan Cancer Foundation, and Director of Epidemiology, Detroit Health Department. Panel -- St. Louis.

Jeffrey P. Koplan, M.D., M.P.H. Dr. Koplan is the Director of CDC's Center for Chronic Disease Prevention and Health Promotion. He is also a Visiting Professor of Community Health, Emory University School of Medicine, and Clinical Professor of Community Medicine, Morehouse Medical School. He is a past Assistant Director for Public Health Practice, CDC. Panel -- Atlanta.

Marshall W. Kreuter, Ph.D. Dr. Kreuter is Director, Division of Chronic Disease Control and Community Intervention, Center for Chronic Disease Prevention and Health Promotion, CDC. He is a past Director of CDC's Division of Health Education. Panel -- El Paso.

James Marks, M.D. Dr. Marks is the Deputy Director for Public Health Practice with CDC's Center for Chronic Disease Prevention and Health Promotion. Panel -- Jackson.

Gordon E. Robbins, M.P.H. Mr. Robbins is Assistant Director for Program Operations at CDC's Center for Chronic Disease Prevention and Health Promotion. He is a past Chief of CDC's Field Services Branch, Division of Nutrition, Deputy Division Director, Division of Nutrition, CDC, and Health Educator, Los Angeles County Health Department, California. Panels -- Sacramento, Phoenix.

Rich Rothenberg, M.D., M.P.H. Dr. Rothenberg is Assistant Director for Science, Center for Chronic Disease Prevention and Health Promotion, CDC. He is a past Director of the New York State Department of Health's Division of Epidemiology and Medical Epidemiologist with CDC's Sexually Transmitted Disease Program. Panel -- Newark.

National Cancer Institute Panelists

Linda E. Bass, M.P.H. Ms. Bass is Director of Minority Health Education Programs, Office of Cancer Communications, NCI, National Institutes of Health. She is a past Director of the National Council of Negro Women's Health Division and National Program Coordinator and Regional Director of the National Health Screening Council for Volunteer Organizations. Panels -- Jackson, St. Louis.

Tyson Lee Gibbs, Ph.D. Dr. Gibbs is Program Officer of NCI's Special Population Studies Branch. He is a past Scientific Administrator of the Gerontology Center at Meharry Medical College, Nashville, Tennessee; Assistant Professor, Department of Preventive Medicine, University of South Carolina; and Expert, Health Promotion, National Institutes on Aging, National Institutes on Health. Panels -- Atlanta, Newark, Sacramento.

John W. Horm Mr. Horm is Director of Data Coordination and Analysis for NCI's Special Populations Studies Branch. He is a member of the American Indian Health Care Association, American Statistical Association, International Society for Environmental Epidemiology. He is a past senior statistician in NCI's Demographic Analysis Section and served as NCI liaison with American Cancer Society for statistical issues. Panel -- Phoenix.

Elva Ruiz. Ms. Ruiz is the Director of NCI's Hispanic Cancer Control Program. She is a past Program Analyst with the Office of Planning and Evaluation, National Institute of Child Health and Human Development, and a Public Health Advisor with the State Assistance Branch, National Institute on Alcohol Abuse and Alcoholism. Panel -- El Paso.

Legislator Panelists

Steve Banton. Representative Banton serves on the Consumer Progection Committee, the Commerce Committee, the Government Review Wrokers' Compensation and Civil and Criminal Justice Committees of the Missouri House of Representatives. He is a partner is the law firm of Quinn, Ground and Banton. Panel -- St. Louis.

Chet Brooks. Senator Brooks is Dean of the Texas Senate and Chair of the Senate Health and Human Services Committee. He helped establish the Legislative Task Force on Cancer in Texas and the Texas Cancer Council, of which he is a current member. Panel -- El Paso.

Tyrone Carrell. Representative Carrell is a member of the Health and Ecology Committee in the Georgia House of Representatives. Panel -- Atlanta.

Ed Beulow. Representative Beulow chairs the House Public Health and Welfare Committee in the Mississippi House of Representatives. Panel -- Jackson.

Wynona Lipman. Senator Lipman represents the 29th District in the New Jersey Senate. She chairs the Senate State Government Committee and sits on the Senate Appropriations and Finance Committee. Panel -- Newark.

Diane Watson. Senator Watson chairs the California Senate's Health & Human Services Committee. She has served on the Board of Education for the Los Angeles Unified School District and was an associate professor at California State University, Los Angeles. Panel -- Sacramento.

Earl Wilcox Representative Wilcox serves on the Health and Aging Committee and the Appropriations Committee for Municipalities in the Arizona Senate. He is a past board member of the Friendly House Barrio Youth Project. Panel -- Phoenix.

APPENDIX D

REGIONAL COMMITTEE MEMBERS

ATLANTA - REGIONAL HEARING COMMITTEE

Jeanne Cashman
Co-Chair
Public Assistance Task Force
Ursuline Academy
Wilmington, DE

Pat Hampton
Department of License and Inspection
City County Building
Wilmington, DE

Tracy M. Walton, Jr., M.D.
President
DC Division
Washington, DC

Dan Blumenthal, M.D., M.P.H.
Chairman, Department of Community
Health & Preventive Medicine
Morehouse School of Medicine
Atlanta, GA

Mary Gullatte, R.N., M.N.
Head Nurse 6-B North
Emory University Hospital
Atlanta, GA

Melba Hill, R.N.
Nursing Administrator
Fulton County Health Department
Atlanta, GA

Mary Clowers
Volunteer
American Cancer Society
St. Petersburg, FL

Myrna Gust
Acting Director Health
Rehabilitative Services
Dade County Public Health Department
Miami, FL

Bernellyn Carey
Project Director, Diabetes Program
Baltimore Health Department
Baltimore, MD

Elizabeth Ward
Assistant to the Mayor's Representative
at Dunbar
Baltimore City Government
Baltimore, MD

Barbara Hager
Health Educator
Division of Health Services/
Adult Health Section
Raleigh, NC

Lee Monroe, Ph. D.
Senior Education Advisor
Administration Building
Raleigh, NC

Charles Johnson, M.S.P.H.
Health Educator
University of South Carolina
Columbia, SC

John Ureda, Dr. P.H.
Chairman, Department of Health
Promotion & Education
University of South Carolina
Columbia, SC

Alvin Bryant, M.D.
Division President & General Surgeon
Hampton, VA

Maston T. Jacks
Deputy Secretary of Human Resources
Office of the Governor
Richmond, VA

Robert Hammer
Volunteer
American Cancer Society
Fairmont, WV

Joan Ross
Executive Director
Southwestern Community Action Council
Huntington, WV

Michael Westbury
Chairman, Committee on Socio-Economics
Distadvantaged in West Virginia
American Cancer Society
Wheeling, WV

JACKSON - REGIONAL HEARING COMMITTEE

John B. Lowe, Dr. P.H.
University of Alabama at Birmingham
School of Public Health
Birmingham, AL

Jim McVay
Alabama Department of Public Health
Montgomery, AL

David T. Allen, M.D.
Director of Health
Louisville & Jefferson County Board of Health
Louisville, KY

Geraldine Chaney, M.D.
Private Practioner
Jackson, MS

John Kelley, Ph.D.
Director of the Regional Family
Service Center
Department of the Navy
Naval Construction Battlion
Company, Family Service
Gulf Port, MS

Louis J. Bernard, M.D.
Meharry Medical College
Nashville, TN

Ken McCullough, Ph.D.
Executive Director, Adult Education
Tennessee Department of Education
Nashville, TN

NEWARK - REGIONAL HEARING COMMITTEE

Suzette Benn
Director
Division of Preventable Diseases
Connecticut State Department of
Health Services
Hartford, CT

Christine Parker
Cancer Control Program
Division of Preventable Diseases
Connecticut State Department of Health Services
Hartford, CT

Selma George Morris
Nurse Educator
Boston University School of Health
Boston, MA

Alonzo Louis Plough
Director
N.E. Health and Poverty Action Center
Chestnut Hill, MA

Kate Rogers
Clinical Oncology Director
Lake Region General Hospital
Manchester, NH

Elizabeth Benson, M.S.W., M.P.H.
Executive Director
Sellement Health & Medical Services
New York, NY

Nilda Bueno, R.N.
Katy's Personalized Placement, Inc.
Smithtown, NY

Blossom Ferguson, R.N.
Nursing Supervisor
St. John's Queens Hospital
Queens, NY

Serena V. Ferguson, M.D.
White Plains Hospital Center
White Plains, NY

Sandra Gagliardo, M.P.H.
Director
Nassau County Department of Health
Mineola, NY

Ann Howard
Director of Senior Citizens
Dole Community Center
Mt. Vernon, NY

George Lopez
Volunteer
American Cancer Society
East Elmwood, NY

Myles Matthews, M.B.A.
Director, Governmental Affairs
New York City Transit Authority
Brooklyn, NY

Barbara Oldwine
"Community Scene" WICZ TV-40
Binghamton, NY

Nancy Reyes, R.N., M.S.N.
AIDS Coordinator
NJ State Department of Health
East Orange, NJ

Adewale Troutman, M.D.
Medical Director
Newark Department of Health
& Human Services
Newark, NJ

M. Judith Garner, R.N., M.N., C.R.N.P.
Department of Health
Cancer Control Program
Harrisburg, PA

Barbara Johnson
Office of Mental Health
Department of Public Welfare
Harrisburg, PA

Carl Mansfield, M.D.
Chairman, Department of Radiology Therapy
Thomas Jefferson University Hospital
Philadelphia, PA

James Maxey, Ph.D.
Executive Director of Bureau of
Charitable Organizations
Harrisburg, PA

Carol Demarco Cummings, Ph.D.
Assistant Professional Health Education
Rhode Island College
Providence, RI

Rose A. O'Kello, Ph.D.
Division Office of Special Projects
The International Health Institute
Providence, RI

Alan Hark
State Health Planning Agency
Vermont Legal Aid Inc.
Montpelier, VT

Joan D. Stern
National Vice President Division Services
East Metro Group
American Cancer Society
Washington, DC

ST. LOUIS - REGIONAL HEARING COMMITTEE

Margaret McClusky, R.N., O.C.N.
Curaflex Health Services
Evanston, IL

Rev. Jerry Stephenson
Hoosier Valley Economic Opportunity Corporation
Jeffersonville, IN

Carol Zingula, R.N.
Nursing Instructor
Kirkwood Community College
Marion, IA

Dr. Don Coleman
College of Osteopathic Medicine
Michigan State University
East Lansing, MI

Jean Mershon
St. Louis County Health Department
Duluth, MN

Clara Maddox
Director, Home Care Department
Samuel U. Rodgers Community Health Center
Kansas City, MO

Robert Johnson
Hospital Administrator
St. Louis Regional Medical Center
St. Louis, MO

John Anderson
Program Coordinator
American Cancer Society
Omaha, NE

John C. Ray
Volunteer
American Cancer Society
Dublin, OH

Charles J. Alexander, Ph.D.
Milwaukee Multicultural Affairs
Milwaukee Area Technical College
Milwaukee, WI

EL PASO - REGIONAL HEARING COMMITTEE

Deborah O. Erwin, Ph.D.
Medical Antropologist
Arkansas Cancer Research Center
Little Rock, AR

Tyrone C. Greene
Volunteer
American Cancer Society
Little Rock, AR

Larry Daniels, M.D.
David Rains Clinic
Shreveport, LA

Pamela Harrison
Volunteer
American Cancer Society
Shreveport, LA

Jean Davis
Nurse Educator
W.W. Hastings Indian Hospital
Tahlequah, OK

Patricia Kelly
Director of Public Education and Training
American Cancer Society
Oklahoma City, OK

Michael P. Dany
Vice President for Program
American Cancer Society
Texas Division, Inc.
Austin, TX

Lovell A. Jones, Ph.D.
Chairman
Department of Gynecology
M.D. Anderson Cancer Center
Houston, TX

Eva Moya, M.S.W.
Social Worker
Centro San Vicente
El Paso, TX

Ann Marie Oria
Area Medical Affairs Director
American Cancer Society
Area I Office
El Paso, TX

Barbara Watkins
Adminstration Office
Parkland Memorial Hospital
Dallas, TX

SACRAMENTO REGIONAL HEARING COMMITTEE

Veva Becker
Volunteer
American Cancer Society
Fairbanks, Alaska

Dileep Bal, M.D.
Chief, Chronic Disease Branch
California Department of Health Services
Sacramento, CA

Jennie Cook
American Cancer Society
Larkspur, CA

Sharen Muraoka
Director of Media Relations
American Cancer Society
California Division
Sacramento, CA

Rev. Frank A. Chong
Executive Director
Waikiki Health Center
Honolulu, Hawaii

Edna Kanani Mariano
Executive Director
E Ola Mau
Honolulu, Hawaii

Margaret Miyashiro
Community Health Services Associate
Molokai, Hawaii

Doreen Akkerman
Senior Research Associate for
Community Organization and Planning
United Way of the Columbia-Willamette
Portland, Oregon

Mary Hudzikiewicz
President
American Cancer Society, Oregon Division
Eugene, Oregon

S. Ross Fox, M.D.
General Surgeon
Auburn, Washington

PHOENIX - REGIONAL HEARING COMMITTEE

Eleonore L. Curran, R.N.
Volunteer
American Cancer Society
Tempe, AZ

Mary Jo Duvall
American Cancer Society
Arizona Division
Phoenix, AZ

Roger Meinershagen
Volunteer
American Cancer Society
Phoenix, AZ

Jackie Miller
American Cancer Society
Arizona Division
Phoenix, AZ

Mary Sue Richards, R.N.
Oncology Nurse
Community Health Agency
Scottsdale, AZ

Ellen Richardson
American Cancer Society
Arizona Division
Phoenix, AZ

Margie Cook, Ph.D.
Professor
Metropolitan State College
Denver, CO

Shelli D. Clemens
American Cancer Society
Idaho Division
Boise, ID

Barbara Andreozzi
Extension Agent
Courthouse
Anaconda, MT

Mandy A. Canales
American Cancer Society
Nevada Division
Las Vegas, NV

Theodore C. Marrs, M.D.
Acting Executive Director
Diagnostic Center for Handicapped Indian Children
Albuquerque, NM

Emelin Martinez, R.N., B.S.N., O.C.N.
University of New Mexico
Cancer Treatment Center
Cedar Crest, NM

Gar Elison
Utah Department of Health
Community Health Services
Salt Lake City, UT

Linda Campbell
American Cancer Society
Wyoming Division
Cheyenne, WY

APPENDIX E

CATEGORIES OF HEARING TESTIFIERS
AND REGIONAL COMMITTEE MEMBERS

COMPOSITION OF PLANNING COMMITTEES
ACS REGIONAL HEARINGS ON CANCER AND THE POOR

Categories of Organization/Individual	ATL	JCK	NWK	STL	ELP	SAC	PHX	TOTAL
Medical Schools	2	1		1				4
Cancer Centers			1		2		1	4
Health Clinics			2	3		2		7
Hospitals			1		2			3
Practicing Physicians	2	1	1		1	1		6
Nurses			2					2
Local Health Departments	4	1	1	1				7
State Health Departments			4			1	1	6
Gov't Social Service Dept.			2					2
Academic Institutions		1	2	1				4
Health Educators	3	2	2	1	1		1	10
Community Health Organizations	1		1	1	3	4	7	17
Voluntary Organizations	3	1	2	2	2		4	14
Community Service Organizations	1		2	1		1		5
State Government	1							1
Local Government	2							2
TOTAL	19	7	23	11	11	9	14	94

STATEMENT

SUBMITTED BY

THE WEST VIRGINIA HEAD INJURY FOUNDATION, INC.

TO THE

PEPPER COMMISSION

FOR THE RECORD OF

THE HEARING ON LONG TERM CARE ISSUES

DECEMBER 13, 1989

CHARLESTON, WV

Mr. Chairman,

This statement is submitted by The West Virginia Head Injury Foundation, Inc., a chapter of the National Head Injury Foundation, Inc., a membership organization of persons who have experienced Traumatic Brain Injuries, their families and providers of services. The purpose of this organization is to encourage the development and provisions of services to victims of head traumas and the prevention of this type of injury.

The "Silent Epidemic", as head injury is so named, is responsible for over one million injuries in the United States each year. Over 100,000 people die, and 60-90,000 are left permanently disabled. In West Virginia, alone, there are over 15,000 persons with prevalent disability resulting from head trauma. Over 2,400 injuries occur annually resulting in 400 deaths and 400-600 people who will never return to a "normal life."

SCOPE OF STATEMENT

This statement is addressed in the various proposals

pending before this commission dealing with long term care issues. The commission has received testimony from a variety of witnesses regarding long-term care and the need for such. This organization will not duplicate these analyses, but rather focus on those points where it's particular expertise may be most helpful - the special relationship between traumatic brain injury and long term care.

Most people who sustain traumatic brain injury are often young. Many suffer residual deficits of monumental proportions from brain injuries, leaving them with complex cognitive and physical problems. Progress to recovery is often very slow and many never fully recover.

NEED FOR LONG TERM CARE

As this population ages, there will be more elderly people who will need varying levels of support to live with dignity. As medical science continues to improve its lifesaving techniques, there will be more victims of trauma who will survive with severe disabilities. Few have coverage for services they require and the effect on them, their families and providers of care who serve them is "catastrophic."

The long term care issue is a very important part of the focus of the state associations of The National head Injury Foundation. We urge that any Long-Term Care Legislation that may be developed focus on two points: First, the needs of younger, disabled victims of trauma, and second, the need for

group homes and care at home as a viable alternative to institutionalization. These group situations must be segregated from other disabilities because the dynamics of head injury is much different than other disabilities. Most of these people are going to receive some kind of long term care, from acute care to group homes, to supported employment or supervised independent living. Families who wish to care for their loved ones at home should not be penalized by reduced SSI Benefits and other financial support.

PREVENTION

While it is perhaps beyond the scope of this Committee's jurisdiction, the organization which submit this statement wish to note that there are steps which can be taken by the Congress to prevent certain catastrophic injuries. As we struggle with the question of provision and payment of long term care of victims of catastrophic injuries, we certainly should address the prevention of such injuries.

We live in a risk-prone society where speed, alcohol and the failure to deal with both responsibly lead to many catastrophic injuries.

The fact that long term care costs are viewed as a national problem is indicative of the fact that the societal cost of catastrophic care is beyond the capacity of states. We suggest that national solutions are warranted. Using federal highway funds as both the carrot and the stick, states should be required to have mandatory seat belt laws,

mandatory helmet laws for both bicycles and motorcycles and requirements that all motor vehicle operators have insurance coverage adequate to cover long term care costs associated with severe injuries such as traumatic brain injuries.

If the federal government is going to be the ultimate insurer of many of these injuries, it is certainly logical for the Congress to aim at the causes of many of these injuries.

SUMMARY

In summary, we suggest that in fashioning a long term care bill this commission consider the youth of our nation who are so adversely affected by traumatic injury. The recommendation in this brief report are only a starting point in a problem that continues to plague this country. We are only in the early stages of this epidemic which will haunt us in years to come if systems are not put into place.

CONCLUSION

The West Virginia Head Injury Foundation, Inc. strongly supports the enactment of a long term care legislation bill. We believe it should include elements of the populations bypassed by the administration in the past. This issue is a primary need of those persons experiencing catastrophic incidents.

This organization will be pleased to provided more detail on the points discussed above as well as personal incidents at the request of this commission.

Thank you.

Respectfully submitted,

Michael W. Davis

Michael W. Davis
Executive Director
West Virginia Head Injury Foundation

ncjw-wvs
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Testimony
Pepper Commission Hearing
December 13, 1989
Charleston, WV

presented by
Helaine Rotgin, Board of Directors
National Council of Jewish Women. WV Section

The National Council of Jewish Women is committed to comprehensive, affordable and available health care - including mental health care - for all. We believe it must emphasize prevention and health maintenance. We furhur believe that substance abuse and addiction are medical as well as social problems and accordingly, need to be part of all health programs.

We underscore the concerns expressed here and all over the country for the uninsured and underinsured; for the lack of care and of providers in our rural areas and for those in economic poverty everywhere.

We furthur express our outrage that we have failed in the past to see as sound public policy adequate investment in our citizens - if not for ethical reasons for economic reasons. The credit card mentality that has characterized our systems ignores the reality that it is eroding the future economic base that theoretically will pay the bills.

Public investment in health care, basic needs and social services is demanded now - a true defense of our country.

We would gently remind the Commission to maintain a sensitivity to several factors:

* the interdependence of successful health services and programs with other services as transportation, child care, etc.

* the current humiliation to spend down into poverty in order to afford care;

* the categorical nature of current programs that is driving our system of care, resulting in forcing needs into adequately reimbursed services rather than determining what is best for the individual in need.

A flexible system that provides a full continuum from prenatal to death, including addressing long term care needs of children and adults, is demanded. We are convinced that such an investment by our country will yield savings far beyond that which can be accurately predicted (e.g. prenatal care, WICS , EPSDT all have immediate econmic savings, but which do not factor productivity as better students, productive citizens, etc.as part of the savings or gain).

The provision of quality health care, affordable and accessible to all, demands no furthur delay.

MEDICARE AND THE ROLE OF THE SOCIAL AGENCY IN
THE PROVISION OF CARE FOR THE ELDERLY

I am Manuel J. Viola, President and Chief Executive Officer of Family Service-Upper Ohio Valley located in Wheeling, West Virginia. Family Service is a nonprofit, accredited, community-based social service agency. It is in its 80th year of service to the community and citizens of Wheeling and neighboring communities. In 1988, this agency served 20,782 clients, 87% of whom were elderly citizens. Like all accredited family service agencies this agency is governed by a board of volunteer community leaders through whom our accountability to the community is maintained.

I am pleased to have been given the opportunity to submit written testimony. I wish to commend and congratulate Senator Rockefeller and the other members of the Pepper Commission for the time and energy they are giving to this important topic of national concern.

Historically, family service agencies throughout North America have made contributions to their communities in a variety of ways: through provision of high quality social services to individuals and families; through provision of family life education programs and through coordination of community services as needed by their clients. They also do advocacy as needed in behalf of clients to improve the care delivery system. Consequently, family service agencies have heavy involvement in the arenas of case management and in the provision of high quality social services.

I wish to present at this committee my concern with the present limitations of the Medicare system with regard to reimbursement for the kinds of services often needed by elderly clients who are at risk of institutionalization. For example, recently I was awarded a research grant by the Health Care Financing Administration (HCFA) to provide case management, home health aide services, chore services, companion services and transportation care giver and participant services to 120 Alzheimer's patients who are at risk of institutionalization. This funding will last for three years. During the funding period, HCFA is permitting Medicare to reimburse our agency for the case management and other services provided to these clients. The irony is that at the end of the three year funding period, my agency will once again revert to the status of not being eligible under Medicare for reim-

bursement for these same services to the same clients. The decision by HCFA to permit this reimbursement under Medicare for these services to Alzheimer's patients for this three year period is very encouraging. For too long, this country has viewed services to the elderly for purposes of reimbursement as the domain of only the medical establishment without regard to human service programs. Yet, the kinds of services needed by a huge number of elderly citizens in this nation, in order to limit institutionalization are those provided by agencies such as Family Service.

While recognizing that Medicare is already a costly program, I also think it is important to keep a perspective on the fact that the costly nature of the program today may stem from the very way that we have structured care to the elderly under federal programs. The kind of care most often reimbursed is often the most costly care. It is not surprising that whatever Medicare decides to reimburse is that which is often utilized for services needed--whether it fits the best needs of the clients or not.

Social services, we believe, can play a very important role in the lives of elderly citizens whose needs are often multiple and interdependent. I urge the Congress and the Pepper Commission to examine at some length the role of the social agency in the emerging care delivery system of this nation. A report issued by Family Service America in 1988 states: When the elderly person is not in need of acute medical care, nor of long-term institutional care, arrangements must be made for periodic physician review and monitoring. However, the physician typically has neither the skill nor the knowledge to identify the range of community resources which would be helpful to the clients, to arrange for the client to receive these services, and provide follow-up contact to ensure that the services are actually provided. The social worker is probably the more appropriate team leader when home-based care is the plan of choice for the client.

Finally, I would like to make some observations about growing trends in corporate America and the greater utilization of the family service agencies for purposes of providing important network services to the elderly. My agency and most accredited family service agencies in North America are members of a National Organization known as Family Service America -- a 78 year old nonprofit headquarters for agencies such as mine. In recent months, major corporations have come to FSA to ask that they be formally connected to the network of family service agencies around the

country. The goal of these corporations is to provide needed services to their employees' elderly family members. This action, in part, recognizes (1) that social services are an important piece of the continuum of care for the elderly and (2) that family service agencies are especially suited to providing an array of services to other community resources.

In closing, let me thank the Commission once again for the work it is undertaking in the health care system for the elderly in the country and for allowing me to submit this paper.

Sincerely,

Manuel J. Viola, ACSW, LCSW
President/Chief Exc. Officer